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1 Executive summary

Cancer52 was invited to participate in the NCSI research work stream to map the research questions relating to the survivorship needs of people affected by the less common cancers. We organised an event for our member organisations, to which they were encouraged to bring people directly affected by the less common cancers (survivors and carers), and used the Knowledge Café model to manage the sharing of information.

The discussions were structured according to the survivorship stages and cross-cutting themes of the NCSI pathway model but it is apparent that the pathway does not accurately reflect the journey for all of those affected by the less common cancers.

A broad range of issues emerged on the day, some of which are particular to the less common cancers including:

- Diagnostic delays as a result of low awareness amongst GPs as well as the general population of the symptoms of the less common cancers.
- The lack of specialist centres for the treatment of many of the less common cancers and the impact this has on treatment and organisation of care.
- The lack of effective second line treatments for many of the less common cancers. In some cases there are none that are recognised by the National Institute of Clinical Excellence.
- Difficulties in the workplace as a result of lack of awareness amongst employers and colleagues of the needs of people with less common cancers.
- Feelings of isolation – people living with a less common cancer find it harder to network with other survivors in a similar situation locally.
- The physical effects of the disease and treatment and the impact on self-image.
- The loss of fertility particularly associated with the gynaecological cancers and the impact on self-identity.
- The need for emotional support and/or psychological treatment to enable people affected by the less common cancers to live as full a life as possible.
- Limited access to key services that are routinely available for patients affected by the more common cancers – including access to counselling and psychological services.
- The lack of support and information for people caring for those with less common cancers.

A number of research questions addressing the above issues have been formulated and are set out in the report.
2 Introduction

The National Cancer Survivorship Initiative (NCSI) is conducting a piece of work to map the cancer survivorship journey and to identify for each point on that journey what is, and what is not, known about the survivorship needs of people affected by cancer and the interventions available to meet these needs.

The mapping project has been completed for the four major cancer sites: breast, prostate, bowel and lung through a process of internal and external stakeholder consultation and the next step is to identify the survivorship needs of people affected by the less common cancers.

Cancer52 is a consortium of organisations representing the less common cancers, so named because 52% of cancers deaths are from the less common cancers1. Cancer52 has 38 member organisations – a list of these can be found in appendix I.

Cancer52 was invited to participate in the NCSI research work stream to map the research questions relating to the survivorship needs of people affected by the less common cancers.

This is a complex task as, whilst there are many issues and experiences which are shared across the less common cancers (and many which are also common with the four major cancers), there are vast differences between the different cancers. Testicular cancer, for example, has a survival rate of more than 95%2 with short, sharp treatment (surgery and a short course of chemotherapy and/or radiotherapy); patients are typically back at work within weeks. At the other end of the survival spectrum, oesophageal cancer has a poor prognosis, with an overall five-year survival rate below 10%;3 it is treated with radical, life-changing surgery and patients are likely to be incapacitated for many months. Of course there is also enormous variation between individuals suffering the same type of cancer. Some will not experience symptom-free remission. Some will experience long periods of stable disease. Some will be diagnosed with advanced disease.

The survivorship model is only a 'best fit' – it can’t be one size fits all.

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1 Office of National Statistics 2004
2 Orchid Cancer Appeal
3 Methodology

To help us complete the mapping exercise we organised a stakeholder event in June 2009 to ascertain the views of our member organisations and the people they represent.

58 people attended the event, including representatives from 23 of our member organisations. Members were encouraged to bring cancer survivors and/or their relatives and carers to the event; 29 people directly affected by the less common cancers were present on the day.

We used the Knowledge Café model to manage the sharing of information. Each table at the Knowledge Café had a facilitator to keep the conversation moving and to scribe the information being shared. A central facilitator led the day, mediating the discussion and drawing out emerging themes.

 Participating organisations were asked to bring their knowledge and experience to consider the care and support pathway and cross cutting themes based on the NCSI pathway model.

Members not able to attend the event were given the opportunity to contribute their views by email. In addition members were invited to submit a detailed pathway analysis for their particular cancer based on the NCSI model alongside citations of recommended research and grey literature. This information, where provided, is included within the appendices and has been drawn on in the drafting of this report.
4 What is cancer survivorship?

Macmillan Cancer Support defines a cancer survivor as ‘someone who has completed initial treatment and has no apparent evidence of active disease, or is living with progressive disease and may be receiving treatment but is not in the terminal phase of illness (the last six months of life), or someone who has had cancer in the past’.

Delegates were first asked to explore the term ‘cancer survivorship’ and what it means to them.

At its most basic the term was taken to mean living with and beyond cancer. Within this, several themes emerged.

– Maximising quality of life – for those who will live and those who will die. For self and for family. Survivorship is about more than simply being alive.
– Regaining control of life.
– Establishing the ‘new normal’.
– Feeling less complete. Not ill but not well.
– Living in the shadow of recurrence.
– Prolonging life through changes to lifestyle.
– Guilt at surviving.
– Anticipatory grief.
– Being grateful to be alive.
– Overcoming fear of death.

There was a sense that the survivorship process is every bit as hard as the illness itself: ‘being ill is easy, not being well (i.e. recovery phase) is the hardest part and continues for a long time’.
5 The stages of survivorship

Many of the aspects of survivorship which were discussed related to more than one stage (without necessarily falling into one of the ‘cross-cutting themes’). Some of the issues – including many of the psychological issues – arise at diagnosis and evolve as the patient negotiates the survivorship pathway.

This section and the next follow the structure of the survivorship stages and cross-cutting themes of the NCSI pathway and the research questions are included as they emerge. Section 7 highlights those issues which are specific to the less common cancers, grouped according to some key themes.

5.1 Remission/follow-up

The issues pertaining to the remission/follow-up stage fall into two broad categories: rehabilitation and adaptation; and prevention of recurrence.

Rehabilitation and adaptation

Survivors felt that the experience of having had cancer left them changed – both physically and mentally. Some of this was positive: ‘Enjoying every morning because you might not have been there’; but participants also broached the concept of ‘post-traumatic stress’ and discussed the difficulties of dealing with the consequences of their disease and their treatment: ‘I’m not the man I was.’ One participant in remission for several years described herself as ‘not ill but not well’. Health professionals need to recognise that people may be disease-free but not free of the disease.

Many participants described how they felt abandoned after their primary treatment finished, left in limbo and uncertain what to do next. Psychologically patients feel safe and cared for during primary treatment and face an anxiety about coming off treatment, finding it difficult to cope when left to their own devices. Diagnosis is often delayed with the less common cancers as there is less awareness of the symptoms amongst GPs. Where this happens, there may be a breakdown of trust between the patient and their GP and this can compound the sense of abandonment.

The concept of anticipatory grief was discussed. It is a process through which those affected by cancer (including both patient and caregiver) can experience the stages of grief – including disbelief, anger, depression, sadness, emotional fragility and constant crying, guilt and then acceptance – even before the actual passing. It is a reaction to the shock of a cancer diagnosis and is essentially a ‘mourning period’ where both the patient and caregiver must come to terms with the fact that the life they knew is gone and they will have to adjust to the ‘new normal’. The mother of a brain tumour patient described her experience: “For the first 18 months after my son’s diagnosis, I barely survived, neglecting my own health and mental well-being and experiencing periods of intense depression and despair.”

Survivors emphasised the constant fear of recurrence – it becomes a life-long preoccupation for them and follow-ups can cause mental ups and downs for many years after treatment finishes.

On the physical side, there is a clear need for support in re-building people’s physical condition post-treatment – and in helping them deal with the long-term
effects of their disease and treatment - including advice on diet, exercise and reconstructive surgery.

People also need help in dealing with the physical changes which may result from surgery – both visible changes such as external scarring and invisible changes such as the effects of oesophageal surgery which impact on lifestyle. [This is discussed further under 5.5 Long-term effects].

Participants suggested that an individual rehabilitation plan would be a useful tool – to help people create their ‘new normal’ and enable them and their family to achieve the best possible quality of life post-cancer diagnosis. They also felt that examples of ‘good survivors’ would be useful – to demonstrate what can be done after treatment.

Also tied up in rehabilitation is return to work/education. Participants felt that information should be provided for employers, to help them know what to expect from the returning employee. Similarly there needs to be some kind of infrastructure in the education system to support children/young people when they return to school/college post-cancer. These points are explored further under the Cross-cutting themes of Information (6.2) and Self-management (6.3).

Attention must also be given to the needs of the caregiver. Their needs can often be overlooked. Material submitted by a consortium of brain tumour charities stated “The fatigue, depression, grief and challenges of day-to-day living which are often faced by a patient diagnosed with a primary malignant brain tumour can also be experienced by that patient’s caregiver.” One of the caregivers included in their report, a woman whose sister has a malignant brain tumour, was quoted as saying “There is a constant knot in my stomach and a huge build-up of stress from MRI to MRI. Caring for someone with a brain tumour feels like you can never take a deep breath.”

As well as having the functional ability to look after the patient’s physical needs, the caregiver must have the emotional health to deal with the psychological impact and, in the case of those affected by brain tumours, the neurological sequelae. Participants called for support and information specifically targeted at caregivers and this is explored further under the Cross-cutting theme of Information (6.2).

Prevention of recurrence (including monitoring, follow-up etc)

Fear of recurrence is ever-present for cancer survivors. They live with the constant expectation that the cancer will come back. Many survivors reported feeling like a hypochondriac or worrying that they were being a nuisance to their GP or other health professionals.

People have information needs relating to prevention of recurrence: information on signs and symptoms to look out for, information on who to contact for help and advice, information on ways to minimise the risk of recurrence for example through diet and lifestyle choices.

The frequency and type of follow-up checks varies between different cancer types, but may also vary depending on the medical team, the treatment centre or other variables. Different centres also vary in the speed of return of results – some hospitals manage to tell patients within hours, other hospitals take weeks
or even months to report results. There is a need for support whilst awaiting the results of these tests.

Participants pointed to the importance of co-ordinating the role of, for example, consultants, GPs, dentists, optometrists, and other health care professionals to promote early detection of recurrence and to the need for improved communication between these different groups.

A couple of specific points relating to paediatric patients/survivors were raised: there is a need for clear cross-over between child and adult services to ensure continuity of care. And there was some concern about how much child cancer patients are later told of their illness – this is important in relation to their ability to detect signs and symptoms of possible recurrence in later life.

Research questions – remission/follow-up stage:

- What guidelines exist for the follow-up care of people with a less common cancer?
- What is the most appropriate means of follow-up and who is the most appropriate person to take the lead?
- Is there any risk stratification – to identify groups most at risk of recurrence or secondary cancers?
- How can we promote better co-ordination between the different groups of health care professionals that could play a role in the early detection of recurrent cancer?
- What cross-over exists between paediatric and adult services?
- How can people (both patients and caregivers) be supported in dealing with the psychological impact of their diagnosis? Specifically, what support systems and coping mechanisms would help them to deal with ‘anticipatory grief’ and to adjust to their ‘new normal’?
- What is the psychological impact of key events in the remission/follow-up period? How can people be supported through this?
- When are people ‘clear’ and when can they be told?

5.2 Recurrence

The new themes to emerge during the recurrence stage involve the psychological impact of a recurrence of cancer and, wrapped up in this, a need for better information and support – at the right time.

Finding out that your cancer has recurred is a devastating blow. Feelings of shock, anger, depression and denial are common. Communication with health professionals is very important during this stage. People need help in managing their expectations – through the provision of information about what will happen next, what treatment options are available and how effective they are. People also need to be informed about their right to a second opinion.

There is a level of fear about further treatment. People have gone through gruelling treatment once only to see their cancer return. They need to have the necessary information to enable them to weigh up their options and assess the benefit of treatment versus the impact on their quality of life. Is it worth going
through treatment again if it is unlikely to work? This especially applies to multiple recurrence – when do you stop treating?

An issue particularly affecting people with less common cancers is that there are generally fewer treatment options available for the less common cancers than for the major cancers. With many of the less common cancers there is only ‘first line’ treatment. If that fails or if the cancer returns, there are no further treatment options.

Research questions – recurrence:
• What further treatment options exist for treating recurrence of the less common cancers?
• What patient information is available on treatment strategies for the less common cancers?

5.3 Active/advanced disease
In the words of one survivor, this is a ‘full on place’. A number of themes emerged.

The arrangements for care of patients beyond the hospital setting are reported to be at best complex and at worst patchy. Access to specialist nurses with appropriate knowledge for less common cancers is not good.

Participants called for a ‘system navigator’ to guide them through. There is a need for greater clarity concerning who is responsible for the patient beyond the hospital team – whether it should be the GP, social worker or other social service professional. Whoever assumes responsibility must be able to respond rapidly to patients’ changing circumstances.

During this stage people expressed a need to ‘make the most of what they have’. They need information and support in deciding where to have care.

Complementary treatments can play an important role in maximising quality of life – but more research is needed to establish the benefits. Help with other lifestyle choices such as diet is required.

The importance of access to palliative care services was emphasised and it was felt that such services (including Macmillan nurses) should be better publicised to break down taboos which still exist. These services should be offered as part of the patient pathway at an early stage to provide support along with information on the options available at the end of life.

Research questions – active/advanced disease
• How can tertiary NHS/social services best respond to the rapidly changing health and personal circumstances of patients with active/advanced cancer and their families?
• What is the best structure for care of the patient beyond the hospital team? Who should assume primary responsibility for the patient?
• What is the best way of prioritising patients/families according to need? Health status? Economic status? Psychological status?
• What role can complementary therapies play in enhancing quality of life for people with active/advanced cancer? What evidence is there for the effectiveness of such therapies?
• Is there any evidence for the impact of lifestyle choices such as diet on quality of life and prognosis?

5.4 Remains well

Many of the issues relating to this stage are similar to those outlined under Remission (5.1 above) – including fear of recurrence, the impact of follow-ups, problems with continuity of care.

Longer-term psychological issues emerge – issues around dealing with the ‘cancer label’ and the social stigma of being a cancer survivor. The less common the cancer, the greater the stigma is likely to be as there will be less understanding and awareness amongst family, friends and acquaintances. Self-image issues are also common at this stage – feeling less of a man, less of a woman, dealing with scarring and physical impairments.

Participants reported feelings of aimlessness at this stage - a difficulty in structuring days and weeks when they have finished treatment but are unable to return to work and are suddenly at home all day. Many reported feeling ready to give something back, wanting the opportunity to help others in a similar situation.

The subject of genetics was raised here. There are two aspects: firstly concern about whether people diagnosed with one cancer are genetically predisposed to cancer and are thus inherently more likely to develop another cancer; and secondly the risk of their children (or future children) developing cancer. One cancer for which this is particularly relevant is retinoblastoma (Rb) - people diagnosed with Rb themselves face an increased risk of developing a second cancer and also risk passing the condition on to their children.

It is not clear the extent to which patients (and/or parents) are told about these risks – and this point relates to the issue raised in section 5.1 above about the amount of information given to survivors of childhood cancers. There are also implications for the education of GPs and other health professionals. One Rb survivor explains:

"When I was 14, I had pains in my knee. I repeatedly visited my GP, who put it down to growing pains. I am unsure at what point the dangers of genetic Rb were known, but sadly, I understand now that this story is still repeated today. GPs are very slow in diagnosing bone cancers in teenagers.

I was x-rayed at my local hospital on my mother’s demand, but it was said to be clear. Two weeks later I fell downstairs and it was discovered that the x-ray had been mis-read and that I had an osteosarcoma in my knee."

Research questions – Remains well

• How can services be developed to help reduce the anxiety caused by check-ups and significant anniversaries? What is the psychosocial impact of such worry?
• What are patients’ needs post formal follow-up. How do they get back into the ‘system’?
• How do people with less common cancers get help with creating their ‘new normal’ and adjusting to it? What psychological services are available to help them?
• Where cancers are known to have a genetic component, what information is
given to patients regarding i) the risk of developing a second cancer and ii)
the risk of their children (or future children) developing cancer? Are there any
measures in place for long term monitoring of these patients (and their
children)? And how can GPs and health professionals be made aware of the
risks?

5.5 Long-term effects
The long-term effects vary across the different cancers and different treatments
– and include psychological, physical and social effects.

People need information on what to expect so that they are not taken unawares.
This information should be provided even before treatment commences so that
individuals can take an informed decision about whether to go ahead with
treatment – some of the treatment-related effects were said to be ‘worse than
cancer’.

Long-term psychological effects include ‘chemo brain’, feeling a lack of control,
the social stigma of being different and feeling like less of a man or woman. But
there are positive aspects too: survivors reported having a more positive attitude
to life, prioritising the important things and not getting bogged down by
trivialities.

The long-term physical effects identified by participants include scarring, reduced
physical abilities (which place restrictions on activities and work options), fatigue,
changes to appearance, premature menopause (and fatigue related to the
accompanying constant hot flushes and sleep deprivation), lymphoedema and
infertility. Some effects are specific to the less common cancers (and the
treatment of) including blindness and paralysis (brain tumours), swallowing and
speech difficulties (mouth and throat cancer), coping with a stoma (stomach
cancers, ovarian cancer); diabetes, hernias and incontinence (pancreatic cancer);
nerve pain and physical disability.

The issue of long-term effects is particularly pertinent to children and young
adults as the impact on physical, social and cognitive development may be very
significant.

Fertility is an issue particularly affecting people with certain of the less common
cancers - such as testicular cancer and ovarian cancer. For patients with these
cancers, fertility will be directly affected if not by the cancer then by the
treatment (which usually involves surgery). For other cancers, chemotherapy or
radiotherapy treatments may lead to infertility. There is a need for advice,
information on options such as sperm banking and egg harvesting, genetic
counselling where relevant and help with issues to do with sexuality.

Participants highlighted the lack of ongoing services to support people in dealing
with the long-term effects of cancer. There is a lack of primary care knowledge
about long-term effects and some health care professionals reportedly have the
attitude that ‘you are lucky to be alive’. The following experience, told by a
cervical cancer survivor whose lymph nodes were removed, highlights the
problems that people face:

"My treatment whilst in hospital was excellent, but at no time was lymphoedema
mentioned. One day, approximately eighteen months later, I began to feel
extremely ill with a severe headache and nausea which lasted for a couple of
days. I also noticed a burning rash had appeared around my groin which spread down my left leg. I immediately visited my doctor who was completely baffled and sent me to the local hospital where a skin sample was taken to check for cellulitis, by this time my leg had started to swell considerably and I was becoming increasingly worried about what this may be. I later got the results from the skin sample which came back negative.

Over the next 12 years I had regular check-ups at my local hospital and on each occasion I asked the doctors about my leg. No-one seemed to know what was wrong and one doctor actually told me to think myself lucky I was alive, never mind complaining about my leg!

Throughout all this I continued to work full time and tried to cope with my swollen leg by wearing trousers when I could find a pair that fitted my swollen leg. I also bought the strongest support tights I could find, thinking these would help, which I wore with skirts. There were some days when my foot was so swollen I could not get shoes on at all.

After moving home in 2000 I registered with a new GP and mentioned my lymphoedema to her. She immediately referred me to the Macmillan unit at the local hospital where I have been receiving treatment for the past few years. I was given several sessions of MLD [Manual Lymphatic Drainage] and this, together with a compression stocking has made an astonishing difference to my leg.

I know there is no ‘cure’ for lymphoedema but knowing that there are people out there who understand the condition helps me to cope. It has taken me around 14 years to get treatment despite me constantly pestering the doctors on the visits to hospital, none of whom seemed to know what it was, let alone how to treat it.”

Long-term effects need to be given higher priority and health care professionals need to recognise how debilitating they can be. There is a need for more interventions – and complementary therapies could be important but they are largely unproven and can be expensive – especially if there are required on a long-term, ongoing basis. More research is required to establish their effectiveness.

In general it was felt that there is a lack of information and research on the long-term effects of the less common cancers and the treatments for these. No one is collecting statistics on late-effects as patients disperse. There is a lack of qualitative information on outcomes generally.

Research questions – long-term effects

- What are the long-term effects of the less common cancers and the treatments for these? How are these being monitored in individual patients?
- What is the incidence of lymphoedema following all types of cancer including the less common cancers?
- What ongoing services exist to support patients dealing with the long-term effects of cancer? What is the most appropriate infrastructure for delivery of such support?
- What role could complementary therapies play in the management of the long-term effects of cancer?
5.6 **Second and subsequent treatments**

One of the major new themes to emerge in relation to this stage concerned continuity of care. Health care professionals often lack knowledge about the first cancer when treating second cancers or recurrence of the first cancer, with different occurrences often being treated completely in isolation. This is a problem particularly affecting the less common cancers as people are less likely to come under the care of a specialist centre.

As discussed under the Recurrence stage (section 5.2 above), there is a need for patient information on treatment strategies for the less common cancers. People need to know what treatment options are available and what the additional treatment effects might as it is perceived that these could be worse than the primary treatment effects. Information should be available on less debilitating second treatment options – for example a lumpectomy rather than an orchidectomy for testicular cancer.

Further treatments simply do not exist for some of the less common cancers and there was a call for more funding for research into the development of such treatments.

Psychological issues particularly relevant to this stage include a fear of failure, and feelings of lack of control.

**Research questions – second and subsequent treatments**

- What, if any, systems are in place to ensure continuity of care for patients undergoing second and subsequent treatments? Is there less continuity for patients with less common cancers?
- What further treatment options exist for treating recurrence of the less common cancers?
- What patient information is available on treatment strategies for the less common cancers?
6 Cross-cutting themes

6.1 Work and finance

Cancer can have serious financial implications.

People affected by cancer, including carers, face a drop in income if they need to take long-term leave from work. At the same time, they are likely to face increased costs. Many people must travel long distances to specialist treatment centres on a regular basis incurring not only travel costs but also accommodation expenses. This especially affects people suffering from the less common cancers as they are more likely to have to travel a greater distance to a centre of excellence (if one exists).

Benefits

The benefits system is complicated and difficult for patients to navigate. In addition, benefits staff are often ill-informed about cancer and its long-term effects – even more so in relation to the less common cancers. Medical assessors for DLA are not cancer specialists. Participants reported people diagnosed with terminal cancer being turned down for DLA by benefits staff who simply didn’t understand the implications of the diagnosis. There is a clear need for better training for benefits staff. In addition, the availability of a skilled key care worker to help negotiate benefits and other such matters would be a considerable advantage.

The embarrassment of having to explain about certain male/female cancers may deter some people from seeking benefits.

A cancer-specific benefits information pack available from GP/CAB/hospital would help to promote better access to benefits and enable cancer patients to receive the benefits to which they are entitled.

Employment

There is a prejudice against those who have had cancer and this is exacerbated for the less common cancers as employers have less awareness and understanding of the condition. People living with or beyond cancer may be seen as a burden by employers and dismissed from existing jobs or turned down for new jobs on the basis of their illness.

The cancer survivor may not be able to return to his or her previous role. Depending on the cancer type, the loss of cognitive and/or physical function as well as fatigue and psychological issues may impact on his or her ability to work. Employers can help by being flexible on hours to allow for hospital appointments etc, allowing a gradual return to work and setting realistic objectives. Access to occupational health therapists would be useful but it is not routinely offered – GPs can refer.

Support for carers is patchy. They also need flexibility at work. They may have become the sole bread-winner yet have competing needs because of their caring responsibilities.

Employers often do not provide reliable advice about employees’ rights but unions can offer advice and support.
Self-employed people can face enormous difficulties and may end up losing their business if they are not able to earn money to stay afloat.

Young patients face the challenge of starting out in career with gaps in education and CV and a lack of confidence and skills.

**Insurance**

Being a cancer survivor increases premiums for travel insurance, medical insurance, mortgage insurance and life insurance – even years later. There is a lack of understanding in the finance/insurance industry although specialist brokers do exist.

**Research questions – Work and finance:**

- What are the information needs of the employer, the employee and work colleagues to facilitate a successful return to work? And how does this relate to the needs of carers?
- What is the appropriate level of support to enable children to return to education or adults to employment?
- What protection does the Disability Discrimination Act afford people living with and beyond the less common cancers?
- Is there a greater incidence of discrimination against people living with and beyond the less common cancers compared with those affected by the four major cancers?
- What is the scale of the employment problem? How many survivors of working age are looking for work?
- How can the knowledge of welfare staff about cancer generally and the less common cancers in particular be improved?
- How far do people with less common cancers have to travel to get specialist care and what are the financial implications of this? Is there any financial support available?
- Why does the insurance industry not fully understand the impact of a cancer diagnosis on risk for different situations? How can we ensure that they are better informed about cancer – and the actual risks?

**6.2 Information**

With information comes empowerment – it helps people to understand their rights and have the confidence to demand what they want.

There is generally a lot of information ‘out there’ but it can be hard to navigate and difficult to judge which information is reliable. Too much information, much of which can be conflicting, is difficult for patients to deal with: ‘I didn’t want to go online and be terrified’.

However specific information on less common cancers may not be universally available in all locations.

There is a need for a more structured delivery of information to patients, family members and carers. People need to be guided through. The information needs to be clear, up-to-date and accessible – perhaps developed with input from survivors.
HOW the information is given is crucial. Information needs to be delivered at an appropriate time in an appropriate way – and what is appropriate will vary between individuals. Those with communication challenges (such as visual loss, hearing loss or non-English speakers) need special consideration. Health care professionals could be more creative about the delivery of information – and could explore delivery by methods such as email, text messaging, peer information as well as verbal and written means.

It was suggested that newly diagnosed patients could be given an information pack with patient information and contacts and sources of further help. In addition, the availability of nurse specialists for patients to contact/visit after treatment for information and advice would be helpful, as well as a drop-in centre for survivors – a ‘listening ear’, a sign-post for relevant information, care and support.

The central message was perhaps that it is not a case of one size fits all. Different patients have very different information needs and one group came up with the idea of ‘information prescriptions’ – bespoke information tailored to the needs of the patient and reflecting their different levels of understanding (which may vary with age, socio-economic status etc).

As far as information content goes, the following specific needs were identified:

- Information on the disease itself
- Information on treatments options
- Information on side effects and how to deal with them
- Information on long-term effects (of both disease and treatment)
- Information on aftercare
- Information about entitlement to a second opinion
- Information about the signs and warning symptoms of recurrence - and what to do if detected
- Information on fertility issues and options
- Information on clinical trials (although these were acknowledged to be scarce for the less common cancers)
- Information on benefits and other help available to both patient and carer

Participants were uncertain as to whether health care professionals are empowered to inform family members/carers as well as the patient. This is particularly relevant where there are mental capacity issues (which may result from some brain tumours). The information and support needs of the children of cancer patients should also be considered.

Caregivers have their own specific information needs. The mother and caregiver of a brain tumour patient wrote “Had I been better supported as a caregiver, the first year and a half of our cancer journey could have been much more tolerable. I could also have provided a much high level of support and care had I, as the caregiver, been able to access more information in a timely manner and understand what my own survivorship needs were, as well as my son’s.” The following components were identified as being important for caregivers:
A ‘systems navigator’ to help steer patient, caregiver and family through the maze of post-operative care, providing guidance on securing benefits where appropriate, providing information on the practical aspects of day-to-day living (both for the patient and the caregiver) and also signposting to organisation and agencies who might be able to assist or answer questions related to the cancer survivorship journey.

Information on coping mechanisms and support systems for caregivers.

Education about critical skills for caregivers – including practical skills such as how to lift a patient properly without risk of damage to the patient or caregiver; how caregivers can communicate better with doctors; how caregivers can be better supported if they are suffering from depression; tips for caregivers about maintaining their own health; readily available respite care information; support groups for caregivers etc.

As well as addressing the information needs of patients, family and carers participants identified other key groups who need information/education on cancer (particularly the less common cancers), treatments and long-term effects. These include:

- Benefits staff
- Schools/colleges/universities (who also need help in coping with children whose parent has cancer)
- Employers
- GPs and other health care professionals

Research questions: Information

- What information is available at the different stages of the cancer journey and how is it accessed? Do people ‘get stuck’ at a particular stage?
- What are the best information points? And what is the best infrastructure for delivery? To what extent do people need one to one support with a clinician?
- What are the different preferences for receiving information and how do health professionals assess what is best for each patient and their family – including when to provide, how, whether self-directed or supported, one-off or continuous and level of understanding?
- What factors affect the type and level of information that people require – e.g. gender, age, socioeconomic status – and how they prefer to access this information?
- What role can/should the internet play in the delivery of information? How can it be policed to ensure accuracy of information?
- What are the specific information needs of caregivers? And what is the most effective delivery mechanism for information to caregivers?
- What are the consequences of poor or lack of information provision on people affected by cancer (including family members)?
- At what age do children get told full information about their condition?
- What are the information needs of i) benefits staff; ii) educational establishments; iii) employers; and iv) GPs and other health care
professionals to help them support people affected by cancer? How can information be delivered effectively to these groups?

- How can the experience of people who have already gone through less common cancer be used to help develop information resources (for health care professionals, cancer patients, employers)?
- Is it possible to standardise information across the UK?

6.3 Self-management

The two central themes in discussions about self-management were **empowerment** and **support** – themes which crop up repeatedly above. Ability to self-manage depends on where people are on their pathway – it is not an option for everyone.

People affected by cancer need help to reassert control over their lives, to have the confidence to navigate the system and to deal with the psychological and physical impact of their cancer. Information needs are dealt with above.

A key element is support – people affected by the less common cancers can be left feeling very isolated. Some patients keep problems hidden from others for various reasons (e.g. employment prospects, not wanting to worry family etc) – and this could further impact on their psychological wellbeing.

Access to support/activity groups could help people to develop social networks, build confidence and share coping strategies. Such groups need to be clearly signposted. People affected by the less common cancers face greater sociodemographic constraints in this regard simply because of the scarcity of people affected by the same cancer; online and web groups may be a good option. Dedicated groups need to be established for younger people, rather than mixing them with older people.

Counselling should be made available to patients and survivors – with the option of one-to-one or group sessions.

People affected by cancer need to be given techniques to help them self-manage different aspects of their lives; they aren’t given this kind of help at the moment – and some have to find out themselves through other patients.

There are self-management models available from other cancers (such as breast cancer) which could be adapted to suit the less common cancers.

People affected by the less common cancers need to be instilled with the confidence to be advocates in their treatments and to proactively seek help if they have ongoing needs or concerns. They need to have the ability to dip in and dip out of ‘the system’ as they readjust and adapt.

People need help to communicate with others about their situation and what they are managing. They need help in managing their own expectations and in setting goals and objectives for life post-treatment.

The ‘expert patient’ programme has received positive feedback and needs to be promoted more widely.

**Research questions – self-management**

- What evidence is there for the effectiveness of self-management techniques in helping patients in terms of quality of life, side effects etc?
- To what extent are patients and families given the support they require? Is the infrastructure properly designed to maximise patient welfare?
- How does the quality of support vary around the UK, especially away from specialist centres i.e. if people live a long way from a specialist centre, and source of specialist support, how do they get the support they need to self-manage their condition? Are there minimum standards of care?
- What is the best way to provide local support?
- Is there any knowledge of the changing needs for self-management support including psychological support as time progresses? How do people’s immediate needs compare with their longer term needs?
- What follow-up is there to ensure that people are coping?
- Is there any support available to help people come to terms with changes in their body image/appearance? How effective is it?
- Is there any self-management support for children to get back into education?

6.4 Commissioning
Focused resources are required for the less common cancers. Specialist treatment, follow-up care and support services need to be co-ordinated and resourced. But because follow-up care takes place away from the treatment centre, it tends to be unequal. Joined up commissioning is needed to ensure that services are resourced and accessible, that care is followed through beyond treatment at a local level and that people affected by cancer can get to wherever the expertise is – irrespective of geography.

There was a sense, however, that cancer is not a major focus for commissioners and that they merely ‘dabble’ in it, leading to inconsistent outcomes. In particular the commissioners do not know enough about the less common cancers.

Patients don’t understand the commissioning process – and who actually commissions services for the less common cancers - and there is a lack of accountability as a result.

The postcode lottery inevitably cropped up in discussions about commissioning – and inconsistencies in the availability of treatments and services, depending on where people live. This includes the following services:
- Psychological support and counselling
- Specific support for young people
- Support for sexual problems
- Nutritionists and complementary therapies
- Specialist nurses for the less common cancers
- Services for known long-term effects such as stoma, lymphoedema
- Palliative care
- Information resources
There was a call for greater investment in rehabilitation and centres of excellence for the less common cancers as well as in research. The less common cancers don’t seem to warrant research investment, meaning that treatment options remain limited. Some cancers do not have drugs available for primary treatment. There is also a lack of second line therapies for many of the less common cancers. And there are quality of life issues with some of the treatments – such as fertility issues with cervical cancer. There are few clinical trials for the less common cancers – many people were keen to have the opportunity to volunteer for trials.

Research questions - commissioning

- What sets of information do commissioners base their decisions upon? Do they know how many patients, level of need?
- How does the provision of specialist services for the less common cancers match levels of incidence and prevalence and appropriate geographical coverage?
- Is the commissioning system working effectively for specialist services where several commissioners are pooling resources? Is it working effectively for the less common cancers, especially at a local level for specialist needs?
- How much of the PCT budget is allocated to the different cancers? How is the allocation decided?
- How does commissioning of social care and other services fit with health commissioning?
- What is the best way of structuring ‘outreach’ services – should they be purely local?
- How much patient choice is there at the different stages, including end of life? How much should there be? How much does it vary between cancers? Geographically? How is choice portrayed?
- How do patients ensure that they are getting optimum treatment in cases where they cannot access a centre of excellence for their particular cancer?
- Are Improving Outcomes Guidelines for the less common cancers being monitored?
- How much money is spent on research into different cancers?
- Is there a mechanism to translate therapies for the major cancers to treat the less common cancers?
- Is there an optimum ratio of cancer nurse specialists (may be different for different cancers)?
7 Summary – key issues

The pathway does not accurately reflect the journey for all of those affected by the less common cancers. A single pathway could not accurately represent the experiences of people affected by such a diverse range of diseases.

Many people living with less common cancers have experienced delays in getting their diagnosis. This is due to a range of factors including low awareness of their symptoms both among the general population and GPs. Many less common cancers have already reached advanced stage by the time they are diagnosed.

Some of the less common cancers are characterised by stable disease at a time when an individual is not ‘disease free’ but their cancer is being managed and they are living with it. This time in survivorship brings with it specific challenges.

As well as differences in disease-specific symptoms, the different cancers differ in the extent to which resources are available for treatment and care; the effectiveness of treatments; and, consequently, prognosis. All of this affects the experience of the cancer survivor.

Some of the key issues to emerge on the day include:

- Diagnostic delays as a result of low awareness amongst GPs as well as the general population of the symptoms of the less common cancers.
- The lack of specialist centres for the treatment of many of the less common cancers and the impact this has on treatment and organisation of care.
- The lack of effective second line treatments for many of the less common cancers. In some cases there are none that are recognised by the National Institute of Clinical Excellence.
- Difficulties in the workplace as a result of lack of awareness amongst employers and colleagues of the needs of people with less common cancers
- Feelings of isolation – people living with a less common cancer find it harder to network with other survivors in a similar situation locally.
- The physical effects of the disease and treatment and the impact on self-image.
- The loss of fertility particularly associated with the gynaecological cancers and the impact on self-identity.
- The need for emotional support and/or psychological treatment to enable people affected by the less common cancers to live as full a life as possible.
- Limited access to key services that are routinely available for patients affected by the more common cancers – such as access to counselling and psychological services.
- The needs of caregivers. They are also affected by the issues which impact on the care recipient. They need specific information and support to help them cope.

Inevitably, because of the nature of the group and the diversity of diseases under consideration, a broad range of research questions have been generated through this exercise; some are specific to certain cancers or groups of cancers, some are more general. Those themes which relate more specifically to the less
common cancers are set out below, with the relevant questions drawn from sections 5 and 6 above.

7.1 **Availability of specialist resources**

There are fewer specialist resources available for the treatment and care of people affected by the less common cancers compared with those available to people affected by the four major cancers. There are fewer centres of excellence and this impacts on very many aspects of people’s cancer journey. It has implications for the quality of care and treatment, including in the longer-term, but it has important practical and financial implications due to the distance that patients need to travel for treatment.

**Work and finance:**
- How far do people with less common cancers have to travel to get specialist care and what are the financial implications of this? Is there any financial support available?

**Self-management:**
- How does the quality of support vary around the UK, especially away from specialist centres i.e. if people live a long way from a specialist centre, and source of specialist support, how do they get the support they need to self-manage their condition? Are there minimum standards of care?

**Commissioning:**
- How does the provision of specialist services for the less common cancers match levels of incidence and prevalence and appropriate geographical coverage?
- Is the commissioning system working effectively for specialist services where several commissioners are pooling resources? Is it working effectively for the less common cancers, especially at a local level for specialist needs?

7.2 **Organisation of care for continuity and co-ordination of services**

To a large extent, this is related to the point above – if patients aren’t under the care of a centre of excellence (or if the centre of excellence is remote geographically) their care is likely to be more patchy.

**Remission**
- How can we promote better co-ordination between the different groups of health care professionals that could play a role in the early detection of recurrent cancer?
- What guidelines exist for the follow-up care of people with a less common cancer?
- What is the most appropriate means of follow-up and who is the most appropriate person to take the lead?
Active/advanced disease
- How can tertiary NHS/social services best respond to the rapidly changing health and personal circumstances of patients with active/advanced cancer and their families?
- What is the best structure for care of the patient beyond the hospital team? Who should assume primary responsibility for the patient?

Remains well
- What are patients’ needs post formal follow-up. How do they get back into the ‘system’?

Second and subsequent treatments:
- What, if any, systems are in place to ensure continuity of care for patients undergoing second and subsequent cancers? Is there less continuity for patients with less common cancers?

Long-term effects
- What ongoing services exist to support patients dealing with the long-term effects of cancer? What is the most appropriate infrastructure for delivery of such support?

Self-management
- To what extent are patients and families given the support they require? Is the infrastructure properly designed to maximise patient welfare?

7.3 Treatment options
Treatment options are more limited for the less common cancers than for the major four, reflecting the paucity of research into many of these conditions.

Clinical trials are non-existent for many of the less common types of cancer - due in part to the fact that there are simply too few patients to make trials meaningful.

Recurrence
- What further treatment options exist for treating recurrence of the less common cancers?
- What patient information is available on treatment strategies for the less common cancers?

Commissioning
- How do patients ensure that they are getting optimum treatment in cases where they cannot access a centre of excellence for their particular cancer?
- How much money is spent on research into different cancers?
- Is there a mechanism to translate therapies for the major cancers to treat the less common cancers?
7.4 Psychological issues

Psychological issues cropped up at every stage of the pathway as people struggle to deal with the impact of their cancer diagnosis and the effect that it is having on their lives and the lives of those around them.

Although positive aspects to cancer survivorship were identified – a 'joie de vivre’ and a renewed appreciation of the value of life – patients face many ongoing issues on their cancer journey. Participants used the term ‘post traumatic stress’ to describe the psychological aftermath of their illness and talked about ‘anticipatory grief’.

Isolation is an issue particularly affecting people with less common cancers – since these people are less likely to meet others with the same diagnosis. Self-image issues are also important because of the nature of certain of the less common cancers and the treatments for them.

Self-management

- Is there any support available to help people come to terms with changes in their body image/appearance? How effective is it?

Remains well

- How do people with less common cancers get help with creating their ‘new normal’ and adjusting to it? What psychological services are available to help them?

7.5 Long-term effects

The long-term effects of the less common cancers and the treatments for them are perhaps less well characterised than for the major cancers.

The effects vary in nature and severity between the different types of cancer and treatments.

- What are the long-term effects of the less common cancers and the treatments for these? How are these being monitored in individual patients?
- What is the incidence of lymphoedema following all types of cancer including the less common cancers?
- What ongoing services exist to support patients dealing with the long-term effects of cancer? What is the most appropriate infrastructure for delivery of such support?
- What role could complementary therapies play in the management of the long-term effects of cancer?

7.6 Informing others

In comparison with the four major cancers, there is less awareness and understanding of the less common cancers – amongst groups including health and social care professionals, benefits staff and employers. This leads to a greater social stigma, increased levels of discrimination and problems returning to work, securing benefits etc.

As well as the research questions relating to information provision for people directly affected by cancer under 6.2 above, the following questions were identified in relation to the information needs of other parties:
• What are the information needs of i) benefits staff; ii) educational establishments; iii) employers; and iv) GPs and other health care professionals to help them support people affected by cancer?

• How can information be delivered effectively to these groups?

7.7 Genetics
This is an issue that relates to specific cancers including Retinoblastoma (Rb) and the following questions were identified (5.4 Remains well):

• Where cancers are known to have a genetic component, what information is given to patients regarding i) the risk of developing a second cancer and ii) the risk of their children (or future children) developing cancer?

• Are there any measures in place for long term monitoring of these patients (and their children)?

• How can GPs and health professionals be made aware of the risks?

7.8 Children and young people
Children and young people face some very specific issues. Cancers in children and young adults are rare – the most common being childhood leukaemia which affects some 500 children a year in the UK.

There was concern about the child’s knowledge and awareness of their condition. This will obviously vary according to their age at diagnosis and there is likely to be wide variation in the amount of information given by parents to children either at the time of treatment or later in life. This has important implications for self-management especially with regard to detection of recurrence or second cancers.

Continuity of care is an important issue for children with cancer – it is unclear how much cross-over exists between paediatric and adult services.

Children can face great difficulties in returning to education after a cancer diagnosis. They may have missed out on a considerable amount of schooling, they may be left with long-term physical, psychological and cognitive problems as a result of their illness and treatment and they face being stigmatised when they return to the school setting.

The long-term effects of cancer can be very significant for children as they are still developing, not just physically but mentally and socially. Chemotherapy and radiotherapy can affect their growth, it can cause neurological damage in some children and other serious physical problems including heart problems. The child will have to carry these effects with them through the rest of their childhood and through the whole of their adult lives.

Information
• At what age do children get told full information about their condition?

• What are the information needs of [educational establishments] to help them support [children] affected by cancer?

Remission/follow-up
• What cross-over exists between paediatric and adult services?
Work/finance

- What is the appropriate level of support to enable children to return to education?

Long-term effects

- What are the long-term effects of the less common cancers and the treatments for these? How are these being monitored in individual patients?

Self-management

Is there any self-management support for children to get back into education?

7.9 Caregivers

The needs of caregivers can often be overlooked but they are survivors of a cancer diagnosis as well. All of the issues raised above relating to the less common cancers can make the journey more difficult for the caregiver as well as the cancer patient.

This issue was a particular focus for the representatives of brain tumour patients and organisations (Meningioma UK, Samantha Dickson Brain Tumour Trust and the International Brain Tumour Alliance - see appendix X). ‘The fatigue, depression, grief and challenges of day-to-day living which are often faced by a patient diagnosed with a primary malignant brain tumour can also be experienced by that patient’s caregiver.’

Brain tumours can have such devastating effects – depending on the type and grade and in which part of the brain it is located, a brain tumour can affect cognition, physical abilities, personality and emotion. They can afflict people of any age and strike at the very core of a person's being.

As well as having the functional ability to look after the patient’s physical needs, the caregiver must have the emotional health to deal with the psychological issues outlined under 7.4 above and the neurological sequelae of the brain tumour.

There was a call for a programme of support and information specifically targeted at care-givers with the following suggested components:

A ‘systems navigator’ to help steer patient, caregiver and family through the maze of post-operative care, providing guidance on securing benefits where appropriate, providing information on the practical aspects of day-to-day living (both for the patient and the caregiver) and also signposting to organisation and agencies who might be able to assist or answer questions related to the cancer survivorship journey.

More studies and counselling for “anticipatory grief” with information on coping mechanisms and support systems that can be provided to caregivers.

More education about critical skills for caregivers. This could include practical skills such as how to lift a patient properly without risk of damage to the patient or caregiver; how caregivers can communicate better with doctors; how caregivers can be better supported if they are suffering from depression; tips for caregivers about maintaining their own health; readily available respite care information; support groups for care givers etc.
More education for doctors on how to deliver bad news. Frequently both the patient and the caregiver are given the news of a cancer diagnosis together at the same time. The words used by the doctor become imprinted on the mind of both patient and caregiver and if not delivered in an appropriate, sensitive manner can literally scar the attitudes of patient and caregiver towards survivorship and living with cancer.

The development of a “cancer caregivers survivorship model”.

Remission/follow up
How can people (both patients and caregivers) be supported in dealing with the psychological impact of their diagnosis? Specifically, what support systems and coping mechanisms would help them to deal with ‘anticipatory grief’ and to adjust to their ‘new normal’?

Information
What are the specific information needs of caregivers? And what is the most effective delivery mechanism for information to caregivers?
8 List of appendices

I. List of Cancer52 member organisations
II. List of participants
III. Feedback from participants
IV. NCSI survivorship pathway model
V. Submission from Brain Tumour UK: development of a survivorship pathway for glioma patients
VI. Submission from Childhood Eye Cancer Trust: retinoblastoma patient stories
VII. Submission from Oesophageal Patients’ Organisation:
   a. psychological aspects of survivorship
   b. a guide to life after oesophageal/gastric surgery
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VIII. Submission from Lymphoedema Support Network:
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    c. quantitative data analysis
IX. Submission from Target Ovarian Cancer: ovarian cancer survivorship model
X. Submission from a consortium of brain tumour organisations: Meningioma UK, Samantha Dickson Brain Tumour Trust and the International Brain Tumour Alliance - the caregiver’s survivorship challenges
### Appendix I  List of Cancer52 member organisations

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## Appendix II  List of participants

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<td>Barrett's Oesophagus Campaign</td>
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<td>Bernie Byrne</td>
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<td>Meningioma UK &amp; Brain Tumour UK</td>
<td>Ella Pybus, Paul Mansi</td>
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<td>Mouth Cancer Foundation</td>
<td>Vinod Joshi, Ken Mulhall, D Paul Bland, Melanie Brooks, Michael Saunders, Vicki Saunders, Emma Crew</td>
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<td>Samantha Dickson Brain Tumour Trust</td>
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<td>Cancer Research UK</td>
<td>Hilary Jackson</td>
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<td>Cancer52 Secretariat</td>
<td>Adrienne Morgan</td>
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<td>Chair of NCSI Workstream</td>
<td>John Neate</td>
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<td>Consultant</td>
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<td>Organiser Cancer52</td>
<td>Philippa Carr</td>
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<td>University of Southampton</td>
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<td>Writer</td>
<td>Katie Martin</td>
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Appendix III Feedback from participants

33 participants completed the feedback form. Participants were asked to rate the day by circling a score from 1 poor to 5 excellent.

In response to the question “How did you rate the day in terms of: a) Content – the themes covered and discussion and your opportunity to input, the average response was 4.2 and b) Structure – the way the discussion was introduced, managed and concluded 4.0

Participants were invited to comment on any aspect of the day. A representative selection of comments follow:

Enjoyable meeting. Excellent forum for meeting people in a relaxed but professional atmosphere.

A most important informative day and very necessary for the progression of information and support of the less common cancers. Our table felt that the pathway was currently too medically oriented and needs to take more note of the psychological aspects.

Confusing at times but generally good.

Really interesting day and to see the interest and determination people share to improve the lives of people affected by less common cancers.

It would have been useful to have an explanation of what some of the buzz words mean like commissioning.

Excellent overall

Would have liked more time

The facilitators were invaluable. I don’t think the discussions would have been as focused/productive without them.

A little noisy.

Excellent way to gather and exchange info. We need to work specifically on our cancer type to provide valid map of specific issues.

Excellent. Very thought provoking and informative. Plenty of information to take back and share with our clients/stakeholders.

Good to see such a diverse range of interests together in a common cause.

Well done on organising a highly productive day and putting Cancer52 on the map.

Not sure how the day will lead to a clinically robust pathway but look forward to the results

Everyone got a chance to participate. Thanks.
Appendix IV NCSI Cancer Survivorship Pathway Model

Adapted from "An overview of the National Cancer Survivorship Initiative (NCSI) - living with and beyond cancer", Mike Richards and Ciaran Devane, January 2009.

Care and support pathway

Diagnosis → Primary treatment

Survivorship care plan (living document setting out aftercare)

Remission/ Follow up

Remains well → Long term

Recurrence

Active/Advanced Disease

2nd & Subsequent Treatments → EOLC

Cross-cutting themes

Work and finance

Self-management

Research

Information

Commissioning

Factors which impact on survivorship

Clinical

Socio-demographic

Individual

Environmental
Appendix V

Submission from Brain Tumour UK: development of a survivorship pathway for glioma patients

Brain Tumour UK is involved with an NHS Improvement project at SWLondon Cancer Network to develop a care pathway - which will include survivorship - for high grade glioma patients. The project is in its early stages but I just wanted to let you know that although over the next year it should generate some useful results there is currently no survivorship pathway that we can send to you.

Thanks to the meeting, I have now identified three people who in various capacities should be able to help us ensure that the project also produces some research suitable for publication, with the result that the pathway can be promoted UK-wide.

Regarding grey literature, the best overall review of survivorship issues for brain tumour patients comes from Dr Susan Catt at the University of Sussex. The following abstract summarises its findings:

“The diagnosis and management of high-grade glioma has profound effects on patients and their families. Guidance issued by the UK National Institute of Health and Clinical Excellence in 2006 highlighted the lack of good studies of palliative care for patients with this disease. We describe new studies published from 2000 to 2007. High-grade glioma is undoubtedly a challenging research area, and many studies are poorly defined and have small and biased samples.

Limited evidence confirms that patients with high-grade glioma form a heterogeneous population with complex needs. Differing from patients with other cancers, those with high-grade glioma need an integrated input from neurology and neurosurgery, oncology, and palliative care. Research in this area is not for the faint-hearted. The big tasks for future research are to develop and empirically test support initiatives that will help patients, their families, and health-care professionals to deal with this disease on a daily basis. These initiatives should include investigation of the provision of end-of-life care, which is currently a neglected feature of management.”

The reference for the paper itself is:

Appendix VI

Submission from Childhood Eye Cancer Trust: retinoblastoma patient stories

Ffion’s story

I was diagnosed with bilateral Retinoblastoma (Rb) in 1975 when I was a few months old. My grandmother noticed a brown patch in my eye and, despite health visitors telling my mother she was being over-cautious, a doctor did finally detect the problem. I was treated at St Barts hospital under Mr Bedford; I had my right eye enucleated and radio therapy treatment on my left eye.

Vision

My vision has slowly deteriorated since childhood. I recall being able to eg draw detailed drawings of faces/figures and reading larger print. I cannot draw like that now and can only read very large print. No one has really explained to me why my sight should have diminished and I am unsure what will happen in the future. It appears to be a very gradual process, though once I did have a very severe infection in my eye and my sight appears to have gotten noticeable worse after that.

At that point, as I was not under any formal care for my eye (I stopped attending clinic at Barts when I was around 15), I attended outpatients in Cardiff University hospital, but found the team there lacking in understanding. I then went to Moorfields (as it was a famous eye hospital) and was treated. It was found that the lids on my remaining eye did not close properly, so I had an operation where tissue was removed from my inner lip to augment my lower eye lid, making it larger and turning it out as it was turning inwards.

I tried using a scleral lens, but found it difficult. It didn’t really increase my vision – indeed, it made it worse as the lubricating gel I use instead of my own tears would continually cloud its surface. This lens would have given some protection to my cornea, but as it’s pretty tough tissue already, I have decided not to go down this root.

Neither glasses nor the lens have helped with improving my vision as it too poor to respond to such methods of magnification.

As Moorfields is in London and very far from my North Wales home, I am now under the care of the Royal Eye Hospital, Manchester, just for annual check-ups.

I also find it very difficult looking into bright light/sunshine, I understand as a result of the radiotherapy.

Artificial eye

I was given a false eye as a child, but was treated by an appallingly old-fashion ‘professional’. Eyes in jars, dirty hands, not good with children etc. I therefore found it very difficult to remove my own eye – and actually didn’t do so between around 10 – 24 years of age.
I then came under the care of a great eye technician who has relaxed me enough to allow her to remove my eye for cleaning every 6 months. She also arranged for an new eye to be made for me, as my old one should have been replaced as I grew up and was somewhat small. I found this an excellent service as I was free to choose the colour/detail of the new eye.

I haven't had any trouble with my prosthetic eye, which, according to others, looks very real. I have, however, felt rather uncomfortable with the look of my remaining eye as it is rather red and has few eye lashes. People always assume that I can see out of my prosthetic eye! My skull is also somewhat concaved where I received radiation, though I am assured that this is barely noticeable – it feels worse than it looks, perhaps.

Other cancers
When I was 14, I had pains in my knee. I repeatedly visited my GP, who put it down to strains/growing pains. I am unsure at what point the dangers of genetic Rb were known, but sadly, I understand now that this story is still repeated today. GPs are very slow in diagnosing bone cancers in teenagers – even though teenagers are known, generally, not to visit their GPs unless absolutely necessary for reasons other than contraception. In addition, had he asked, he would have discovered that I didn’t do much sport (the only real let-down to being in mainstream schooling).

I was x-rayed at my local hospital on my mother’s demand, but it was said to be clear. Two weeks later, I fell downstairs and it was discovered that that x-ray had been mis-read and that I had an osteosarcoma in my knee. I was treated at the Royal National Orthopaedic Hospital, Stanmore, and the UCH, London. I was given 6 doses of chemotherapy and a massive knee replacement. I have since had a second knee replacement as the first became extremely loose. On that occasion, in 2001, a low grade infection entered my knee and I had plastic surgery to close a hole created by the infection. I now can’t walk more than a mile or two without pain and swelling in my leg and it is extremely scarred.

I think the chemotherapy also had an adverse effect on my vision as it was very drying to my eyes and I recall doctors from St Barts coming over to UCH when the problem got quite acute. My sight was definitely worse in my late teens than it had been as a younger child.

Post-cancer
After I stopped seeing my oncologist regarding my knee when I was given the all clear ten years later, I was not under any oncologist’s care. I think this is a problem in the system for people of my age who are clearly at a higher risk of developing cancer than others. I therefore asked that I be put under someone’s care, if only to have someone to refer to if I am worried, or to suggest certain precautionary measures. I now attend out patients at the teenage cancer unit at Christie’s Hospital, Manchester every year, just so that I am in touch with an oncologist in the right field.

I also underwent a CT scan on my brain to check for any abnormalities, but it was clear. My oncologist didn’t foresee any problems in particular, but thought it was important to have a base-line view of my brain should anything occur in the future.
They had originally wanted to perform a MRI scan, but it transpired that I have a magnet in my eye socket which no one had ever told me about. I have never used this in conjunction with my false eye, to my knowledge, so it was rather disconcerting to have such a thing in my head without knowing, especially as it now stops me from having MRIs, should I need to. I also had an ultrasound of my remaining eye. After some concern over small white masses which appeared there, it was decided that they are merely calcifications from my treatment as a child.

**Life**

I attended mainstream school, with assistance from support workers/technology and went on to achieve good results in my A-levels, a 2.1 in law, politics masters and am now a researcher for the BBC, who are a very supportive organisation. I was fortunate throughout my education as both my parents are teachers, so they therefore knew how the system worked and how to demand support for me. I also had mostly excellent teachers and I am fortunate to be quite academic, so did not struggle with school work.

I was also not bullied at school – perhaps because I’m tall, quite loud and would be likely to hit back! I have always had lots of friends and thoroughly enjoyed university. With the aid of laptops, CCTVs, Braille (my parents demanded that I be given the opportunity to learn it as a child), touch-typing (again, my parents arranged private lessons for me from the age of 6), I have always been well able to keep up.

I own my own house, have lots of friends, travel a lot and am a member of a choir – so generally quite happy! However, being both visually impaired and restricted in my walking is an annoying combination of disabilities as I cannot drive, or do the adventurous things I’d love to do, for example, go travelling alone.

I am aware that I have the genetic form of Rb and would not consider having children unless the eggs were screened. But as I am 33 and have not yet met anyone with whom to have children, I doubt it’s a problem I will have to face.

Having a facial disfigurement, however small, can knock your confidence – in my case, mostly with relationships – flirting etc is a bit difficult when you can’t see very well – but maybe that’s just me! This is the one area where I really don’t have much confidence.

**Changes I’d like to see**

I think that those who have survived cancer need more support and information about what to expect. Specifically for Rb, I am unsure about how my eye will react in the future, why I have a lack of vision etc. I felt that I lost touch with the Rb professionals and did not know who to turn to in a crisis (bad eye infection).

I wasn’t told formally of what to expect as someone with genetic Rb and so a diagnosis of another primary cancer was delayed. I have found out other vital information by chance; that it is important for me to see a dermatologist twice a year as I am at risk of skin cancer, especially as I have lots of moles. That I should be under the care, if only remotely, of an oncologist – not a good idea to be totally out of the loop.
I was offered genetic counselling and know that it is out there if I ever wish to start a family. I feel it is very important for families of children with Rb to be made aware of possible future problems. I also think that young people who’ve had Rb should be put into the visually-impaired loop. I hadn’t really met any else who couldn’t see until I was much older and wasn’t aware of opportunities eg to go on adventure holidays with other VI young people.

Other who’s had Rb may not want to take up such opportunities, but it would have been good to know about them. Going to mainstream school is, I think, the preferable path as it’s the real world – but it does cut you off from others with a similar disability with whom you can relate.

**Jana, 32**

**Diagnosis**
I was diagnosed with bilateral Retinoblastoma at the age of 5 months. My mum was breast feeding me and noticed a strange light refraction in my eyes. She didn’t see it again for a couple of days but a friend then noticed it and was very worried. My mum happened to have read by chance something about Peter Falk (actor) and his experiences with Retinoblastoma whilst waiting for a prenatal check-up (before I was born).

It was 1977 and we were on holiday in my dad’s home country of Slovenia which was a state of Yugoslavia, a communist country at the time. A specialist recognised RB and she told my mum to go back to London to get referred to Moorfields Eye Hospital. The GP in Hampstead took some convincing but he did refer me to the hospital. My mum was told that she would have to wait a couple of weeks for the consultant to return from holiday but that this wouldn’t affect treatment and she would be first to be seen on his return.

I finally had my right eye enucleated at Moorfields on the morning of the consultant’s return and my left eye received frequent doses of external beam radiotherapy at St Bartholomew’s. This formed a cataract (as it always does after radiation treatment) which was removed a few months later and as a rule they did not replace the lens.

As a result of all this treatment, I am registered partially sighted. I have luckily had no other related medical problems as yet apart from weak teeth (apparently also caused by radiotherapy) and a slightly low immune system. I am aware that I have been and will be at a heightened risk of forming other cancers but I have been very lucky so far.

**Condition of my eye today**
I wear a special contact lens in my left eye which partially corrects my vision. It is called a scleral lens and, as it is raised off the cornea, it also keeps the eye moist (I fill it with saline before I put it in). This is really helpful as, like many people who received radiotherapy as standard treatment; my left eye has not got working tear ducts and is therefore very dry.
I used to wear very thick glasses (and still do at times) which left very deep red ridges on my nose and provided me with a very limited field of vision. When I do wear them, I have noticed that my eye reacts to the atmosphere more noticeably and, even with regular lubrication of eye drops, is quite painful. I am not sure whether this is a sign of getting older or as a result of my eye getting used to the lens.

**Prosthetic eye**
My right eye is prosthetic. Everyone whom I’ve told or who has worked it out has been astonished by the good art work, how real it looks and how well it moves. I suffer from eye strain often but it seems to manifest in very acute pain around the bone and behind the prosthesis in the eye socket. I am also very squeamish about the false eye. I really don’t like the fact that it’s not real and I am fascinated in what it’s like to have two eyes. No one can really explain that one to me though they do try.

I hate taking it out to clean it and I wait until it’s really necessary (a few months at a time). Then I need a glass of wine or a spirit before I do it to calm my nerves and I have to be on my own at home. It’s a simple procedure but I have had a phobia ever since visiting an ocularist in Germany when I was three. He really scared me, partly because he was a scary man and partly because he showed me rows and rows of false eyes all staring at me!

**Post-radiation**
Another consequence of the radiation has been that it affects bone, flesh, and eye lash and tissue growth in the area where it was given. This is not so much of a problem these days in western countries as they have better ways of directing the radiotherapy and the standard treatment is actually chemo therapy.

It is quite noticeable on my face and it really bothers me so I cover it with my hair. However, it still gets noticed and I get the usual stare. Children find it either a bit scary or odd and I have to be prepared with answers to questions like “why is your eye stuck back?” Also, my eye lids don’t shut properly which affects me at night. I either cover it with an eye mask and tissue or put in my lens. I do wish there was a magic wand that would correct this. I have learnt to live with poor sight, although I’m sure I could deal with it better, but I still haven’t come to terms with my face. I don’t think I ever will.

**Vision**
In regards to the vision, I do get frustrated. Coming to terms with not being able to drive has been easy as I live in Greater London and transport is ok. I seem to take much longer to do things at work or college, even with visual aids, and that irritates me.

I have a feeling that my vision may be getting very steadily worse and my eye gets tired more easily. I find both distance and near vision difficult. For example; I have trouble seeing bus numbers and reading text messages.

A further result of radiation is that I am photophobic, bright light is quite painful. It makes it difficult for doctors to see into my eye and it’s especially difficult for me to see on bright days when the sun is low in the sky. I also have extremely poor night vision. I am quite independent though and always have been.
Education
I have been schooled in mainstream education. On the whole this was ok. It was inevitable that I would get bullied though and I wasn’t very good at forming a thick skin in protection. It all affected me a lot and I had and still have to some extent, a low self esteem and am naturally a shy person. I was average at school but I do think I could have achieved better results.

My parents were just happy that I was in a state school and getting on with things. I personally think they could have pushed me more and expected me to achieve better grades, like they did for my fully sighted brother. But that was then and they were just happy that I was alive, active and enthusiastic about things which I was and am.

I didn’t get much support through 6th Form and University. I didn’t get very good A’ level results which I really regret as I know I could have done better. I went to a very unsupportive 6th form and felt very low at the time. However, I then did an art degree and got a 2.1 with honours in painting. I can draw pretty well; my teachers at school never thought I would be good at art and were quite shocked when I started producing drawings to accompany my work. I was a bit coy about my disability whilst I was on my degree course and tried to avoid discussing it as much as I could. So, in a way I wasn’t really helping myself.

Work
I do feel that a lot of people become impatient and have a lack of understanding in these areas. I am on school placement as part of my PGCE training at the moment. I have to remind people over and over again that I will not be able to see certain things but I still am thrust a sheet of paper with size 8 writing mid lesson that I am to read out (which I can’t).

I feel also that people can patronise or condescend occasionally and I am not sure whether it is my personality, the way I look or the fact that I am partially sighted. The fact is that there aren’t many partially sighted people in the teaching profession (or disabled people as a whole). I think this should change and I will do my best, although it really is a battle.

I have had long periods of unemployment and have struggled in jobs in regards to my sight. Now I am doing an Initial Teacher Training course (PGCE) teaching primary school children. I am eligible for Disability Students Allowance but I have still to receive the equipment that I need to complete the one year course. I am half way through it already and have struggled greatly.

Genetics
The final point is that, as a bilateral Retinoblastoma survivor I will most likely have a 50/50 chance of passing the gene on to my offspring. I have a boyfriend with whom I am incredibly content and happy and have been for four years. I never pictured myself so happy with a fella. He is definitely one in a million; good looking, kind, clever and considerate. And younger than me by 6 years! So, we have discussed that, when he is ready, we would like to have a child or children. We’ve talked about adoption which we are both very keen on. This is more in regards to the issue of giving someone in real need a home. But I can’t help having incredibly strong maternal broody feelings and would love to have one of my own. So we have to consider the options.
Eliot would far prefer taking chances; it’s less clinical and more intimate. I am not really willing to take chances and the treatments and tests to avoid the RB gene showing up seem more attractive. But we will weigh things up when we are ready and I am sure we will both agree.

So that’s just one perspective of dealing with the aftermath of cancer treatment. Everyone has different experiences which they deal with in different ways but there are lessons to be learnt from all of us survivors.

**Branwen’s story**

My retinoblastoma was first picked up when I was 4 years old by a routine eye test check done by the school nurse. She noticed something wasn't quite right in my right eye and informed my parents. My parents made an urgent appointment at my optician that afternoon who confirmed there was "something unusual" in my right eye, and directed us to our GP the next day. From there, we were referred to our local hospital, and again, from there we’re sent to Moorfields Eye Hospital in London the same week, it was there that I was diagnosed with retinoblastoma in my right eye. I was transferred to Barts Hospital in London where I underwent surgery to remove my eye. The surgery was cancelled for a day or two as a fire broke out in Kings Cross Station during our time in Barts and doctors were needed elsewhere. However, the surgery then went ahead and within a few weeks I was home recovering and back to school within a month or two.

The next step was to have an artificial eye which I had made up at a local Artificial Limb Hospital. I used to have a new artificial eye made up every few years while I was growing as a child. I had regular check ups and screening at Barts throughout my childhood to make sure the cancer did not return in my other eye, as it can be genetic in some cases. Fortunately, I remained clear and I was officially discharged from Barts when I was 14 years old, 10 years after initially having retinoblastoma.

When I was 19, I was offered a blood test to see if doctors could detect the retinoblastoma chromosome in my genes, but they could not, but unfortunately, this does not mean I don't have it, it could be that they simply could not find it, however, signs do show that I do not have the genetic form of retinoblastoma as I only had it in one eye as a child, there is no family history of it, it was the only tumour I had, (but they still can not rule it out).

In 2005 my first daughter was born, who was immediately screened for retinoblastoma, and very fortunately, she had clear and healthy eyes. In 2007, my second daughter was born, who again, was screened and showed to have clear and healthy eyes. Both my children will remain to get screened and checked by the excellent team of specialists at Birmingham Children’s Hospital until they are 5 years of age, after this point, retinoblastoma tends not to develop. They are screened apx every 3 months and so far remain to have healthy eyes.
Steven Pike

When I was 5 I was diagnosed with retinoblastoma and within a week I had my eye removed at moorfields and had cancer check ups at St Barts. I can remember bits and pieces but after that I have lost about 2-3 years where I can not remember a thing. Apparently before I had the operation I was very smart but after, I became very shy and I sort of went a bit backwards and even my speech suffered.

It’s my parents who I feel sorry for. They were younger than what I am now when it happened and I don’t know how I would cope if I was a parent and it was happening to my child. My dad said he couldn’t sign the paper to say; it was the hardest thing they ever had to do.

I had a ghostbusters toy where the eye popped out and dad was using that to explain. But he was crying as he was telling me and he said I told him it will be ok; the innocence of youth.

I know it’s a big thing for the person going through retinoblastoma but I also appreciate that it is also an awful experience for the people around the person going through it.

School
Growing up with retinoblastoma has always been a part of my life so I have always coped. At primary school I never really had any problems, I think there were a few comments but I was always quite open about having one eye and kids were curious. But with curiosity comes the unknown especially in kids and what they didn’t know, they tend to see as different and start to shout out abuse. When I was nearly ten, my mum took me into my class and helped me write together about my experience and what happened to me and after that, everyone came up to me and was a lot more understanding and knew a lot more.

Then I hit secondary school. Pretty much to start with it was great. But things soon got out of hand. The serious bullying came in, starting with verbal threats. Then it soon turned to violence where I was punched and kicked every day for about 2 years. I had all the usual comments such as popeye. I still get the same questions all the time. Can you take your eye out, can you get an eye with a smily face, can you see the brain, can you put your eye in someone’s pint, can you see out of it etc.

When I left school, I gained in confidence and really enjoyed college.

Work
But after college I went into Honda and you would have thought adults would be better but in fact they were worse and I was hit at work because of my eye. It has taken me up to the age of 24 to be able to look at people in the eyes. I was always taught to look at the bridge of someone’s nose but with so much going on, it stopped me from doing that and I always got paranoid people that were staring at my eye.
Since I have moved to Northern Ireland, I have become so confident with my eye as people are a lot more accepting; there are no questions and I’m treated the same.

**New eye**
The first time I got my new eye was a harrowing experience. I was obviously an absolute nightmare and when I got back home to Swindon, I had to see an eye specialist and apparently it took 6 nurses to hold me down as I was kicking and screaming. I remember soon after my parents took me to this old ladies house who had one eye and she took it out and showed me what to do. After that I was ok and have been seeing the same eye specialist ever since and would never trust anyone else near my eye.
Appendix VII

Submission from Oesophageal Patients’ Organisation:

a. psychological aspects of survivorship
b. a guide to life after oesophageal/gastric surgery
c. swallowing – nutrition when it's difficult

Dr Martin Dempster (School of Psychology, Queen’s University BELFAST)

It is well recognised that cancer survivors may experience adverse effects such as anxiety and depression. Interviews and focus groups with a small number of OPA members (by academics from Queen’s University Belfast) highlighted the specific challenges faced by former patients and their carers. As a result, the OPA and Queen’s University have been working together on research to help explain why some former patients and their carers experience greater levels of anxiety/depression than others. Funding for the project was secured from Action Cancer (a charity based in Northern Ireland).

Questionnaires were sent to everyone on the OPA database and a total of 594 former patients and 439 carers returned them. People who responded to the study had experienced a range of oesophageal conditions and all information received will provide useful insights into the experience of patients and carers. However, only a flavour of the results can be presented, so we have focused on the largest group of people in the study; survivors of oesophageal cancer and their carers.

The average age of respondents was 65 and approximately 67% of former patients were male (with most carers being a spouse or partner). On average, former patients had received a diagnosis of oesophageal cancer approximately 4 years before they received our questionnaire. While it is perfectly normal for people who have had a chronic illness to experience some level of anxiety, responses revealed that 35% of former patients and 49% of carers were experiencing high levels. Symptoms of anxiety are the main threat to mental health. Fewer people were experiencing depression (although a small number in the sample did record high levels). So, our main aim was to try to understand why some people experience higher levels of anxiety than others.

Unsurprisingly, people reported being more anxious when they had recently experienced symptoms they associated with oesophageal cancer (and if they had other medical conditions). Also, younger people and people without a carer tended to be more anxious. However, the way people thought about their condition, and the way they coped, had the most important impact on their levels of anxiety. For example, former patients who believed that their illness was caused by stress, overwork (etc) were more likely to report higher levels of anxiety than former patients who were looking to a more positive future. Therefore, we believe that encouraging people to think about their situation differently, and helping them to develop useful ways of coping, could help to improve their mental health.
Specifically, we believe that psychologists and other health professionals could develop ways to help people understand their condition and recognise ways of feeling in control of it. Additionally, helping people to maintain a positive focus appears to be a useful coping strategy, whereas spending time reflecting on the effects of oesophageal cancer, or attempting not to think about the disease at all, are associated with increased levels of anxiety.

Although the research has provided us with a lot of useful information, we would like to send out another questionnaire to investigate if, and how, things might change over time for people. This will allow us to develop a better informed method of helping to improve levels of mental health among former patients and their carers.

We would like to take this opportunity to thank everyone who completed and returned their questionnaire and hope that you may do this a second time in the future. The information you provide really can make a difference.

Finally, as mentioned, it is normal to experience some level of distress when faced with the consequences of a chronic illness. However if you are experiencing such distress we would encourage you to discuss this with an appropriate person, such as your GP, who may be able to provide some help.
A GUIDE TO LIFE AFTER
OESOPHAGEAL/GASTRIC SURGERY
(Oesophagectomy/Gastrectomy)

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1. INTRODUCTION

You have had a major operation and feel that life can never be the same again. It can, with slight modifications, and it can be a very good life. The objective now must be to learn to live with the changes in your system so that they affect your quality of life as little as possible. There is no need for a special diet, you can eat and drink anything you like, but some guidelines may influence the way you eat. For example, for the first 4-6 weeks you should eat food which is soft and well cooked, and adopt a little and often regime. Almost certainly you will develop a greater interest in healthy eating and that will be better for you too. The recovery period is slow, but slow steady improvement is best. It is possible for people to return to their former fitness level in time, including running marathons!!

In the UK the most common reason for the operation you have had is cancer, but it can also be a result of a rupture of the oesophagus, a long-term hiatus hernia, a development from Barrett’s oesophagus, or because of a congenital condition. Continuing research is being carried out on both the causes and treatment.

You may wonder, in the early days, if you will ever recover from this operation which has left you feeling as if you have been under a steam roller. Initially you will need a lot of rest and may feel exhausted by the slightest exertion, but you will notice a gradual improvement. Your recovery will take place over a number of months and some people will take longer than others.

This booklet will help you. It is based on the experiences of people who have had the same operation as you, with valuable input from health professionals.

2. THE OPERATION

**Oesophagectomy**
This operation involves removal of part, or most of the oesophagus (gullet) and part of the stomach, the amount of each varying according to the position of the tumour. The stomach is then moved into the chest and joined to the remainder of the oesophagus. The join may be near the neck or slightly lower and all or only part of the stomach may be in the chest. To help healing of the join you may have been fed in hospital through a tube up the nose and into the stomach, or perhaps directly into the small intestine (the jejunum) where most of our digestion of food takes place.
Gastrectomy
In this operation, if all of your stomach has been removed (total gastrectomy), the top part of the small bowel (the jejunum) is joined on to the bottom of the gullet (oesophagus). If only part of the stomach has been removed the small bowel is joined to the remaining part of the stomach. This means that the food you eat will pass almost immediately from the stomach into the small bowel. As after oesophagectomy, to help healing of the join you may have been fed in hospital through a tube up the nose and into the stomach, or perhaps directly into the small intestine (the jejunum) where most of our digestion of food takes place. In the future you will need to have regular injections of vitamin B12 from your GP.

Keyhole surgery
Some people have part or all of their surgery performed using keyhole surgery. This means that although the same operation is performed you do not have a large wound. You may therefore recover more quickly, but you should remember that although there is little to see on the surface your body still has to recover and heal and this will take time.

If your feeding tube is still in place when you are discharged you will be taught how to care for it before you leave.

3. SPEED OF RECOVERY

Your GP will be informed when you are leaving hospital. It is quite likely that the district nurse will also be informed especially if you still have a feeding tube in place.

Recovery from a major operation involving digestive organs is not fast. It can take months for the digestive system to adapt after surgery although some patients are quicker than others. It will be some months before you are at your peak again and you will have off days along the way. Try not to be impatient - enjoy the new lease of life.
Initially you will feel very tired, possibly exhausted at times and plenty of rest is needed. Sometimes the tiredness may come on very quickly; don’t feel you have to fight it. An afternoon nap in bed is helpful for the first 5/6 weeks to prevent you getting overtired, or you may find you need to go to bed for several hours during the day and still need to go to bed early in the evening. Take some gentle exercise as soon as you can - walking to start with for just a little further each day - it will help stimulate the appetite. It will also stimulate your breathing, helping the chest to expand and restore its suppleness.

Diarrhoea can be a problem from the early days (see the section on this below). You may also have a dry cough, perhaps when talking a lot or too loudly. This can be helped by sipping a cold drink or sucking a boiled sweet. It disappears in time, but may take a year or more.

4. EATING AND DRINKING

Depending on exactly what surgery you have had, you may now have no stomach at all, or you may have a much smaller stomach. This means that you no longer have the capacity for large amounts of food, but this may gradually increase. The digestion process will be different and it will take a while for you to become used to this. You will feel “full up” more quickly, but the sensation will probably be different. At first it will be easy to overeat, and it will take you a while to judge when you have had enough. You will also find that your sense of taste keeps changing during the initial weeks. You may find that one week you like something and the next you don’t. Keep eating a wide variety of foods.

SWALLOWING
The act of swallowing should not be impaired but some trepidation about food entering the ‘new arrangements’ can make it feel a little difficult and lumpy at first. Staying on a liquid diet should not be necessary. Gradually move onto a normal diet as you feel able. Avoid hard or sharp food pieces during the first six weeks, but well-cooked meat (white in particular) can be included as well as fish without bones. You should be able to manage a normal diet within about six weeks to three months. However, crispy foods such as crispbreads and toast may be easier to manage than soft bread since they don’t absorb as much saliva and become a doughy mass.

Do not be alarmed if in the early weeks you have problems with swallowing. This often occurs due to the join being swollen and tender. See under “Food Sticking”

APPETITE
Many people find they have poor appetite during the early stages of recovery so concentrate on things you like. Initially your sense of taste may be affected with food and drink not tasting of much and possibly a bit unpleasant. You may prefer more sweet or savoury foods than you did before. As said earlier an operation on the digestive system does have major effects, but these vary from one person to another so different solutions are needed. Something not easily digested or liked in the early days may become so after a while. There may have been certain foods or drinks that did not agree with you in the past for whatever reason and these are not likely to change following surgery.
Stimulating the appetite

- A small drink of sherry or other aperitif, or even a small beer, before a meal may help to stimulate your appetite and improve taste.
- Relax and avoid rushing meals.
- Try using a smaller plate and serve meals which are attractive and colourful.
- If you are too tired to prepare a meal, have a ready meal instead.
- If food has no taste, try highly seasoned or marinated food.
- If hot food upsets you, eat it at room temperature or cold.
- If you find cooking smells a problem, avoid the kitchen or use cold or microwaved foods. Perhaps someone else can prepare your food for you. However, for some, the smell of food will tempt the appetite.
- If you do not feel like eating you may supplement a snack with a milky drink; you can fortify the milk by adding dried milk powder to it. Alternatively, have a food supplement or try one of the nutritious drinks listed in the appendix.

MEALTIMES
In the early days talking during meals may affect ease of swallowing. You may like to sit at the table to eat, or prefer to sit in an armchair with a tray on your lap. Some people find it easier to eat with a distraction such as reading or watching TV. Sitting upright helps to avoid any tendency to choke on food.

A microwave oven is useful for reheating food which has gone cold, as may happen if you are eating slowly.

Sit for a while after a meal.

LITTLE AND OFTEN
The key to eating well after surgery is not to eat large meals, but to eat smaller amounts regularly. You may find this difficult at first, but try to eat SIX times a day; three small meals and nourishing snacks in-between. Eat slowly and chew your food well. This will help you digest your food and prevent you feeling full too quickly. You will feel uncomfortable if you eat too much at one time. You will gradually get to know what is the right amount for you.

Eating more frequently can be a pleasure - biscuits with coffee in the morning; a scone or cake with tea in the afternoon; a gap between courses of the main meal of the day be it midday or evening - one is always eating! Try to make it an enjoyable activity - you now have time for conversation, and there’s no need to grumble at slow service when you are eating out!

DRINKING
Drinking is important and you should make sure that you drink plenty of fluids. However, you must be careful not to fill yourself up before or during a meal or you will not want to eat your food. When eating, just take sips of fluid.

There is no reason why alcohol should not be taken but the effect may be felt a little earlier than hitherto - so beware! Moderation in all things! (Remember certain medicines can react with alcohol - look at the label).
**GAINING WEIGHT**

Often people have lost weight prior to surgery and it is quite common to continue losing weight after leaving hospital, maybe for some months, and many people never return to the weight they were prior to their illness. You will establish a new 'fighting weight' in due course. It may take a long time - a year or longer - and by eating little and often you should be able to maintain a good calorie intake. However, if you feel that you need to gain weight there are ways of adding calories to food. See appendix.

**5. SOME POSSIBLE PROBLEMS**

Following your operation it will take your body a while to settle down and you may initially encounter some unexpected experiences. Most of these will subside with time. For instance, if milk seems to be making you ill you can use soya milk instead but consult your dietician as you may need to add a food supplement to maintain your nutrition levels. Keep trying a little milk as the problem should not last more than a few months when the enzyme needed to digest milk starts being produced again.

**DUMPING**

A sensation known as Dumping Syndrome occurs when the food you have eaten passes rapidly through the system and may give rise to some of the following symptoms: dizziness, possibly fainting, feeling very hot, sickness and pain in the abdomen. Diarrhoea or frequent bowel movements may follow. It can be unpleasant and distressing, but is not serious and generally the frequency of attacks becomes less. The effects normally disappear in half an hour or so. For oesophagectomy patients it generally occurs an hour or more after eating (late Dumping). Those who have had a gastrectomy may be more prone to dumping, and this may occur sooner after eating (early Dumping).

In late dumping the sugar content of the food or drink causes insulin to be released by the pancreas. A slight excess of this gives rise to the feelings and some patients have found that quickly having a glucose tablet or sweet can relieve the symptoms

Dumping is a fairly complex subject and we have factsheets available which give more detail.

**GASTRIC RETENTION AND SICKNESS**

Conversely, food can sometimes remain in the stomach rather too long, causing you to feel sick and bloated, with burping. This may occur as you begin to eat slightly bigger meals. It is very common and your GP will be able to give you a medicine (for example, metoclopramide or domperidone) which you should take half an hour before each main meal to improve the motility of the system. You will not need it forever - just until the body gets used to the new arrangements. Major nerves are severed in doing the operation and this is the cause of the problem.

If you suffer more persistent sickness which is not relieved by the above medicines mint or ginger products, the traditional remedies for nausea and sickness, may be helpful.
FOOD STICKING
If you feel that a little food is stuck, try a fizzy drink, which may help to loosen it. If food does become stuck for more than a couple of hours ring for advice from the ward at the hospital where you were treated. Normal eating of solids should not be a problem, given that they are well chewed and obviously not too large.

After surgery scar tissue at the join in the oesophagus may restrict the flow of food or even cause it to stick. This can be worrying and a reminder of the original trouble but it is alleviated fairly easily by dilating it a little in hospital. It is a routine procedure and may only have to be carried out once but a few patients need to have it done several times in the early months. Do not persist with the problem too long; it is better to treat it early. Consult your doctor/ surgeon if you feel this aspect could be improved.

ACID REGURGITATION (REFLUX)
Sometimes an extremely unpleasant feeling in the stomach may come over you for a short while, particularly first thing in the morning. Although there may be no acid burning in the throat the trouble appears to be caused by acid in an empty stomach. The remedy is to spit out as much fluid as you can or, if caught in time, drink some water to dilute the effect and encourage it to go downwards. It should become less frequent in time, but there may always be a possibility of it occurring.

Keeping some food in the system may help to prevent acid or bile from the stomach area actually encroaching on the throat and even into the mouth, which is very unpleasant. It occurs most commonly at night or in the early morning. Some food in the stomach or gut helps to absorb the acid and there are also medicines which can help to prevent its regurgitation (prokinetics) or reduce its formation (proton pump inhibitors - PPIs). Mints or ginger biscuits may make you feel more comfortable.

Extra pillows or raising the bed head by about 4 - 6 inches with blocks of wood or a house brick can be very beneficial, and a pillow under the knee area may prevent slipping down during the night. Electric beds are now available much more cheaply than in the past. If you have had an oesphagectomy, whether you sleep flat or propped up may be affected by the position of the join between the remainder of the oesophagus and the smaller stomach. The higher this is the less reflux may be experienced.

FLATULENCE
You will probably experience a tendency to burp rather more than before. Sometimes it can almost be involuntary but with practice some control is gained and embarrassment can be avoided. Discomfort is relieved and it has to be tolerated since it may remain a long-term effect. You may also find that wind gets trapped in the stomach area. This can be painful and worrying, but it does improve fairly quickly.

DIARRHOEA
Due to the surgery you may suffer from diarrhoea, particularly in the first few months after the operation. It may be accompanied by rather severe colicky pain.
This problem generally eases in time and medicine from your GP can help, but it often seems to occur for no apparent reason, ie it cannot be related to anything you have eaten. You could take a note of what you have eaten that day, just to see if it is food related. It may be wise to reduce intake of high fibre foods and milk for a day or two while affected, ie less fruit, green vegetables, pulses (beans and lentils), high fibre cereals and wholemeal bread. A diet with more meat, fish, eggs and potatoes is likely to be useful in controlling the condition. It’s a nuisance but don’t worry about it, and learn the method of control that suits you best. Diarrhoea can have other causes of course. See your doctor if it persists.

6. A SUMMARY OF NUTRITIONAL GUIDANCE

- Try to eat often – graze throughout the day.
- Sit upright, eat slowly and chew your food well, this will help you digest your food and prevent you feeling full too quickly. Eat soft food (not liquidised) for 4-6 weeks following surgery. Then, normal consistency should be suitable. Ordinary bread can be a problem for a while - try toast, crackers or crisp breads.
- Sip a drink with food if you like, but don’t drink much before meals – it will fill you up. A small aperitif may help such as sherry.
- What you like is best – it stimulates the gastric juices.
- After eating sit still for half an hour and don’t bend down soon (you may regurgitate your food)
- Your last snack of the day should be at least an hour before bed – it can help to absorb stomach acid.
- Food supplements (on prescription) can be useful – good nutrition in small volume – find ones you like. There are many – ask your dietician.
- Do not put too much emphasis on weight gain – it will come in time. It is normal to lose weight after surgery, as you will not eat much for a few weeks. Then it should become stable and gradually increase, but not usually to your original weight. If you are still losing weight after two months or if food sticks on swallowing, speak to your specialist nurse or consultant.
- If you have no appetite speak with your doctor – a short course of steroids may help.
- Further ideas for food are in the appendix.
- Some patients find probiotics (eg Yakult, Actimel, etc) helpful with reflux and digestive problems.
- Nutritious drinks can be very valuable in the diet. Make milky drinks (eg coffee, cocoa, hot chocolate, Horlicks, etc) with full fat milk. You can also purchase Complan, Build-up or supermarket/chemist own brand nutritional drinks, which are available in sweet and savoury flavours.

7. LIFESTYLE AFTER SURGERY

Your aim after getting over your operation may be to become fitter than you were before. However, in the immediate post-operative period, exercise is the last thing you feel capable of doing. Muscles, bones and organs have all been affected in the chest, abdomen, and often the throat. Recovery takes some time; if you were working you are going to be off for some months and it could be more than 12 months or so before you are really at your best, although hopefully you will feel pretty well long before that.
THE FIRST FEW WEEKS
You start exercising very quickly after the operation; the physiotherapist has to get your lungs going again, expelling fluid that can gather as a result of the operation and anaesthetic. This is a rather painful process but effort put in at this time is well worthwhile. As you get out of bed and feel so weak you see the challenge. Walking (or staggering) is about all you can do at this stage. Any effort exhausts you and going upstairs is like climbing Everest, but try walking a little further each day and it will get easier.

Progressive exercise during this early period should be taken by increasing speed or distance - not both. Bear in mind that outdoor walking is more difficult - there may be slopes, a wind and heavier clothing to wear - and don’t forget the return journey!

Look after yourself at this stage, not the housework. Continue the breathing exercises given in hospital - six deep breaths each held for a count of 3 and gently exhaled. Do this 5 or 6 times a day. It can be done sitting up straight or standing. (If there is still sputum coming up you may have been given extra exercises to do - don’t neglect them).

AT HOME
Progress may seem slow, but pushing it too hard will possibly do more harm than good. Don’t try to prove anything; it’s not worth it, the body will take its own time. During this early stage coughing, perhaps occasional sickness, and movement generally will be painful and you may feel that things will come apart inside. Be assured - they will not. If you have had an open oesophagectomy the ribs do take time to repair and it will be a month or two before you can sleep on the side affected. Muscles too have been stitched together but these heal well in about two months; bones and cartilage take rather longer. Nerves, which are necessarily severed in any operation, repair very slowly indeed and some areas around the wound may remain numb.

Surface pain at the wound may occasionally occur for years. Nothing to worry about - it’s the raw nerve endings.

You may feel able to tackle the odd bit of housework after a few weeks but don’t aim to complete it all in one go.

You may find that your ability to concentrate has been affected. This can be very frustrating, but it will gradually return. It may help to take up a new hobby that is not so demanding while you have got time on your hands.

DRIVING
It is probably wise to inform your motor insurance company that you have undergone major surgery before you start driving again. You must be capable of performing an emergency stop. Have a practice run first. There are mental as well as physical aspects to consider and you must feel safe. There will be some pulling on healing muscles, depending on the size of car and ease of steering.
**EATING OUT**
Eating with others is a very social occasion and there is no reason why you should not continue to do this. Friends and family should be aware that you only eat small portions, and in a restaurant ask for a child’s portion or have a starter as a main course. Do not worry about leaving food. If you wish you may explain to a member of staff that it is no reflection on their cooking, but you do not have to do this. The Oesophageal Patients Association has produced a card which states that for medical reasons you can only eat small portions.

**SLEEP**
It may take several weeks to establish your normal sleeping pattern. To avoid pain waking you it may help to take a painkiller before you go to bed. As already stated, you may feel totally exhausted, and an afternoon nap for the first 5/6 weeks is helpful. Some people like to go to bed, others nap in the chair.

Hallucinations and dreams
Some patients may ‘see’ or dream about things they know cannot be happening. This may be related to medication and should gradually happen less. If you find this disturbing it may help to talk to your family or GP.

**PSYCHOLOGICAL EFFECTS AND SUPPORT**
Now that you are recovering you may find that you have an emotional reaction to the events which have taken place. If this is a problem for you try talking to family and friends or your GP. Many patients find it very helpful to talk to somebody who has also had the surgery and the Oesophageal Patients Association will be able to put you in touch with a knowledgeable former patient. There are groups around the country and you can be told about the one nearest to you.

**RELATIONSHIPS AND SEX**
The trauma of being diagnosed with cancer and undergoing surgery often alters our relationships with others. Feelings for our closest family are enhanced and couples may need extra love and reassurance. Both partners may be worried about having sex after surgery. It is normal to feel anxious, but sex should be possible and as enjoyable as it was before. It may be best to wait 4-6 weeks, but allow yourself plenty of time if you feel uneasy about resuming sex. Treat it like any other activity; if you are tired and tense wait until you are ready.

**SMOKING**
If you are a smoker you will have stopped smoking in hospital, so try not to start again. If you need help to stop smoking contact your GP. For further information on the internet look at www.givingupsmoking.co.uk

**GETTING BACK TO NORMAL**
You should be seen by your surgeon within two months of your surgery. Further appointments may then be made but some hospitals leave it to the patient to make contact if they feel the need. Clinic procedures also vary; some doctors will always examine you but others only do so if there is a problem. It is natural for you to worry about the cancer recurring but in time your confidence will grow. If you have any concerns see your GP or contact your specialist nurse.
THREE TO SIX MONTHS ON
We are all individuals but somewhere within this period you should be able to tackle exercise. Perhaps swimming, which is a very good exercise for all ages. Take someone with you to give you confidence and the benefits will soon show. For the non-swimmer (though it’s never too late to learn) walking is good all round exercise as long as you walk far enough and at a fair pace. Cycling and dancing are also suitable as they need not be too strenuous, and as you become stronger any sport that you enjoy can be added, but don’t start with competitive games like squash and badminton and avoid lifting weights. These and sports like running can be added later (up to marathon standard if you are really determined - one of our former patients has run several). If you were previously overweight, now is your chance to keep that new slim figure by taking up a sport that you used to find too energetic.

Activities which involve bending down may cause acid regurgitation. This would apply to some yoga exercises and to gardening (usually weeding) where it can be avoided by squatting or kneeling, and using long-handled tools.

The most important things about exercise are that it should be taken regularly, be strenuous enough to make you puff, and be enjoyable.

BACK TO WORK
The timing of a return to work depends on many factors; age, type of work, effort put into regaining fitness. In any event it may be some months before you do, but we are all individuals. Heavy work makes more demands and might in fact not be suitable if much bending and lifting is involved. Hopefully your employer may be able to help by using your skills and knowledge for lighter work. Initially travelling in rush hour traffic may be stressful and shorter hours for a few weeks will enable you to “run in”. Remember to plan to be able to take nourishment when you need it - little and often. Remember too that for some time you may tire more quickly so if driving or working with machinery is involved extra care and planning may be necessary.

8. APPENDIX - HEALTHY EATING
The following are suggestions only and do not have to be followed. If you have to follow a special diet for medical reasons, you should not change your diet without consulting your health professional.

ADDING CALORIES
- Add extra sugar or glucose to drinks, cereals, desserts and fruit.
- Add honey, syrup or jam to porridge and desserts.
- Melt butter on vegetables, meat and fish and add to sauces and milk puddings.
- Add grated cheese to mashed potato, vegetables and soup.
- Have mayonnaise on salads and in sandwiches, cream in soups, sauces and desserts, and cream cheese on bread and biscuits.
- Put minced meat or flaked fish into soups.
- Make fortified milk (4 tablespoons milk powder mixed into a pint of milk) and use this for your drinks and in cooking in porridge, sauces, soup and milk puddings.
SNACKS AND SMALL MEALS

- Keep snacks to hand so you can nibble throughout the day.
- Nuts, Bombay mix, pasteurised cheese, pate, peanut butter, biscuits, crackers, breadsticks, dips – such as hummus or tarasamalata, crisps, nachos, tortilla chips, pepperoni, cheese dippers.
- Fresh and canned fruit, popcorn, yoghurt, muesli bars, chocolate, sweets, dried fruit, breakfast cereal eg crunchy nut cornflakes.
- Teacakes, muffins, crumpets, croissants

Sandwiches: These can be made from sliced bread, toast, bagels, baguette, chapatti or pitta bread. Fill with cold meats, tinned fish, pate, dhal, hummus, egg, bacon, cheese or peanut butter. Add mayonnaise, pickles, chutneys, salad or avocado to make them more interesting.

On toast: Baked beans, cheese, sardines, eggs – poached, scrambled or fried. Add plenty of butter or margarine and top with grated cheese.

French toast (eggy bread) or omelette: Add cheese/mushrooms/ham

Jacket potatoes: With butter and fillings such as cheese, beans, tuna mayonnaise, chilli con carne, coleslaw, bolognaise sauce, hummus or sour cream.

Ready made meals: Can be frozen, chilled, tinned or boil in bag

Nutritious soups: If having soup as a meal, choose one that contains meat, fish, cheese, lentils peas or beans. Make soup with milk or add cream and serve with a roll.

Pasta: Instant or microwaved pasta with added cheese or ham

Puddings
- Milk puddings such as rice or semolina. Add jam, fresh or tinned fruit or cinnamon and sultanas and brown sugar. Thick and creamy or custard-style yoghurt, fromage frais, fruit mousse or fool, trifle. Tinned sponge pudding,
- Jelly with tinned fruit and ice cream or cream. Add raspberry or chocolate sauce. Hot or cold pie or crumble with cream, ice cream or custard. Waffles or pancake with maple syrup and cream or ice cream. Cheesecake or sweet pastries with cream.
- Baked apple or banana with brown sugar and sultanas. Serve with custard, cream or ice cream.
- Whisk a small tin of evaporated milk into a cooled jelly made with ½ pint water to make a milk jelly.
- Use custard and stewed or pureed fruit to make a fruit fool.
- Banana and chocolate or other confectionery can be chopped into Angel Delight.
- Full fat Greek yoghurt with honey and soft fruit. This can be topped with brown sugar and grilled to make crème brulee.

Adding cream to any pudding will boost the energy content. For convenience try aerosol creams. These keep well in the fridge. Long life cream is also useful.
**NUTRITIOUS DRINKS**
To tempt the appetite, serve chilled in a tall glass or tumbler with a straw.

**Milkshake**
1 cup milk 1 scoop ice cream
1 packet Build Up or Complan – flavour of your choice
Blend all ingredients together and serve.

**Fruit Milkshake**
1 cup milk 1 cup tinned fruit (drained) or fresh fruit
1 packet vanilla Build up, Complan or full cream milk
1 teaspoon sugar (optional)
Liquidise the fruit. Add other ingredients. Blend and serve.

**Coffee Calypso**
1 cup milk 1 packet Build up, Complan or full cream milk
1 teaspoon instant coffee (vary amount according to your taste)
1 scoop ice cream
Dissolve coffee in a little hot water. Add to other ingredients. Blend and serve.

**Choc-mint surprise**
1 cup milk 1 packet chocolate Build up or Complan
2 tablespoons single cream Few drops peppermint essence (to taste)
1 scoop ice cream
Blend or whisk all ingredients together except the ice cream. Pour into glass, add ice cream and serve.

**Yoghurt smoothie**
1 pot full fat yoghurt, flavour of your choice
1 banana 1 packet Build up or Complan
1 cup milk 1 teaspoon sugar (optional)
Blend all ingredients together

**Sherbet fizz**
1 packet vanilla Build up, Complan or full cream milk
1 scoop ice cream 150mls lemonade
Blend all ingredients together and serve immediately

**AFTER RECOVERY**

It can take up to six months for the digestive system to adapt after surgery. When you feel fully recovered from your operation and you are more fit and active you may want to return to a lower fat diet and include more fibre, fruit and vegetables.

If you are still losing weight or experiencing difficulties with eating at this time, contact your dietician or GP.
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OSOPHAGEAL PATIENTS ASSOCIATION

SWALLOWING – NUTRITION
WHEN IT’S DIFFICULT

Former patients
helping new patients

SWALLOWING - NUTRITION WHEN IT’S DIFFICULT

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INTRODUCTION

Difficulty in swallowing may be experienced for a number of reasons; for example, a growth may be being treated by chemotherapy prior to surgery or after surgery if considered helpful; a stricture may need dilatation (stretching); a tube (stent) may have been inserted within the oesophagus (gullet) to make a passageway through an obstruction; or during radiotherapy or laser treatment the ability to swallow may be affected. Whatever the reason, some thought may be needed as to what can be eaten, the nature of the food and its consistency. A diet of soft food often becomes variations on a theme of soup, jelly and ice-cream which can be very boring. This booklet aims to show that it need not be.

IF YOU HAVE A TUBE (STENT) FITTED

Modern stents are made of a wire mesh, generally covered with a thin material. They are easy to insert being encased in a pencil-thin sheath before release opposite the constriction. They usually cannot be taken out again. They come in different internal diameters (usually 9-12 mm) and lengths to suit individual needs. Generally they are held in place by the constriction they are opening up.

Looking after the stent:
- Don’t rush eating.
- Have soft food in small mouthfuls and chew it well.
- Drink a little during and after meals - fizzy drinks are helpful.
- Sit up straight when eating.
- Don’t tackle large lumps of food - cut them up small and chew well.
- Spit out anything not chewed.
- Mix food supplements such as Complan very thoroughly - dry powder will block the stent.
- If you feel the stent is blocked stop eating, drink a little and walk around a bit.
- If the blockage persists for more than 3 hours ring your GP or contact the hospital where you were treated.
- Clean the stent after eating with a drink of soda water or lemonade or use this mixture: 4oz sugar, 2oz cream of tartar, 2oz sodium bicarbonate. Use one teaspoon of the mixture in a half tumbler of water.
- Keep teeth and dentures in good order so that chewing is effective.

Foods to avoid:
- Green salads and raw vegetables
- Fried egg white and hard boiled egg
- Fruit skins and pith of grapefruit and orange
- Tough meat and gristle
- Fish with bones
- White bread, crusty bread and toast
- Shredded Wheat and Puffed Wheat
- Hard chips and crisps
- Nuts and dried fruits
IF YOU ARE HAVING RADIOTHERAPY

Radiotherapy for oesophageal problems can affect taste, make the throat feel tender and very dry, and sometimes nausea and tiredness can add to your difficulties and make you a little depressed. All these matters improve when the treatment stops, but taking the best nourishment you can while it lasts will help recovery. Use the suggestions in this leaflet and ask the hospital dietitian for help if needed. Medicine can be given to reduce nausea.

Generally hot, spicy foods should be avoided and ask about alcohol if you normally enjoy a drink. Fizzy drinks, fruit drinks and even beer may sting as may very hot drinks, but nevertheless try to take plenty of fluids including milk.

IF YOU ARE HAVING CHEMOTHERAPY

Chemotherapy can also affect taste and appetite and cause nausea and vomiting for a day or two after being given. Cold food and drinks may be more acceptable at this time as they avoid cooking smells, and tart and salty flavours (e.g., lemon, crackers) may help. Cut down on fat and keep up the fluid intake as some dehydration can occur. Milk is good if you can tolerate it and fruit juice/Ribena to supply vitamin C, glucose drinks such as Lucozade, fizzy drinks, spring water and herbal teas (if your taste for tea and coffee has changed) are all useful. Fresh pineapple is good for keeping your mouth fresh and moist.

Make use of marinades, strongly flavoured sauces such as sweet and sour, pasta or curry, herbs, spices and seasoning as long as you have not got a sore mouth or mouth ulcers. If you get any cravings go along with them.

Take energy supplements (see below) and see below for the section on feeling sick. It may help to suck a boiled sweet or a mint while the chemotherapy is being given. The second and subsequent doses of chemotherapy may be better tolerated but taste may be more affected particularly if fungal infections occur.

A BALANCED DIET

To get everything you need from your food you should eat at least two foods from each of the following groups every day:

**Group 1:** Bread, cereals and porridge, rice, pasta, potatoes.
**Group 2:** Meat, poultry, fish, eggs, milk, cheese, yoghurt, nuts, peas, beans and lentils.
**Group 3:** Vegetables, salads, fruit, fruit and vegetable juice. Try to include a glass of fruit juice every day.

The body needs to be well nourished in order to be able to fight infection. Normally it has stores of some nutrients, such as iron, which will cover your needs for a short time if you are not eating properly, but will eventually run out. If you eat less food than you need your body can use up its fat stores first, but eventually the muscles will weaken and this will make you feel tired. Also your body tissue will be damaged more easily than normal and it will not heal as well. This is especially important if you have surgery and/or radiotherapy/chemotherapy. The dietitian at your hospital will be pleased to advise you if you need more information about diet.
Each of the following sections must be read in conjunction with the general advice appropriate to your treatment, eg fizzy drinks may not suit during radiotherapy, and fatty foods during chemotherapy. Milk intolerance may be experienced following oesophagectomy and gastrectomy.

**If you need more energy:**
- Add extra sugar or glucose to drinks, cereals, desserts and fruit.
- Use high energy drinks like Ribena and fruit syrups mixed with water or milk or straight from the bottle on ice-cream. Fizzy drinks are good but not the low calorie kinds.
- Put melted butter on vegetables, meat and fish and in sauces and milk puddings. Spread plenty on bread, toast and scones etc.
- Grate cheese into sauces, mashed potatoes and soup.
- Spread jam, honey or marmalade on toast. Stir honey into yoghurt or stewed fruit and have honey or golden syrup on porridge.
- Have mayonnaise on salads and in sandwiches, cream in soups, sauces and desserts, and cream cheese on bread or biscuits.
- Keep snacks by you so that you can eat whenever you feel like it, eg fruit, cheese, biscuits, chocolate, sweets.
- Keep ice-cream, ice blues, full fat yoghurt and other desserts in the fridge for times when you fancy something cold.
- Use special energy supplements from the chemist, flavoured drinks or flavourless powders which are added to foods and drinks (see section on food supplements).

**If you need more protein, eg after surgery:**
- Add milk powder to porridge, soups, sauces and scrambled eggs. Use evaporated milk on cereals and desserts.
- Keep grated cheese in a plastic container in the fridge, ready to put on vegetables, potatoes, soups, sauces, pasta and fish.
- Put minced meat or flaked fish into soups.
- Mix four tablespoons of milk powder into a pint of milk and use this for all your drinks and cooking. Use it instead of water when making condensed or packet soup (see section on food supplements).

**If you need more vitamins and minerals:**
- These are only needed in very small amounts and you are unlikely to be short of anything if you are eating a reasonable quantity and variety of foods.
- Dairy produce (milk, butter, cheese, eggs, yoghurt) and cod liver oil are rich in vitamins A and D; bread, biscuits, nuts, wheatgerm, malt extract and Marmite are good for vitamin B; most vegetables and fruit contain vitamin C, especially citrus fruits and blackcurrants.
- Balanced food supplements like Build-up and Complan contain a wide range of vitamins and minerals.
- Multi-vitamin and mineral tablets are readily available from chemists. If you are not eating meat because your taste is impaired see your GP for a blood test as you may be anaemic and need extra iron. Other sources of iron are beans, pulses, eggs and green vegetables, best eaten together with some form of vitamin C (such as a glass of orange juice) which helps absorption of the iron.
Alternative diets:
Diets based on such things as carrot juice and large doses of vitamins have been advocated by some people in recent years for cancer sufferers but there is not much evidence that they are successful though some people may find them enjoyable. A well-balanced diet is generally recommended.

EATING PROBLEMS

If the ability to swallow is reasonable it may only be necessary to cut food up small or to process or liquidise those items which present problems, such as meat. However, if food needs to be of a softer consistency it may be simpler to blend the whole meal. Processing sufficient for several meals and freezing it in plastic tubs will save time.

A microwave oven is useful for reheating food that has gone cold, as may occur if you are eating slowly.

Not hungry:
• A drink of sherry before meals helps to increase the appetite, but check with your doctor first if you are on medication.
• Eat little and often.
• Make meals as attractive as possible with garnishes, eg parsley or other fresh herbs, tomato, lemon, etc, as appropriate.
• Nourishing drinks can be used to replace some meals - examples below.
• Make foods such as soup, mashed potato, sauces and milk puddings more nourishing by mixing in milk powder, cream, evaporated milk, grated cheese or butter/margarine as appropriate.

Too tired to eat:
• Let others do the cooking.
• If you are on your own you may be able to have Meals on Wheels for a while.
• Use convenience foods; prepare food to freeze when you are feeling well to use when you are tired.
• You may feel more like eating after a rest or nap.
• Have food that is nutritious but easy to eat.
• Eat small meals with snacks in between.

Indigestion and heartburn:
• Have small regular meals.
• Drink an hour or so after meals, not with them.
• Chew your food well.
• Sit upright when you eat and stay like that for a little while afterwards to help the food to go down.
• Peppermint sweets may help.
• Avoid fatty or fried foods.
• Don’t eat within one hour of going to bed.
• Drinking milk or eating yoghurt may help.

Feeling too full:
• Eat little and often.
• Have snacks between meals.
• Chew slowly.
• Drink after, not with, meals.
- Medication (metoclopramide or domperidone) taken 30 minutes before meals may assist stomach emptying.

**Feeling sick:**
- Try to eat little but often.
- Have something dry like a biscuit first thing in the morning.
- Don’t eat fatty or highly spiced foods.
- Keep meals fairly dry and drink an hour or so after eating.
- Try cold foods and drinks - there’s no smell to upset you. Acid flavours like chilled tinned grapefruit are easier to take, or have ice lollies or fizzy drinks such as lemonade, cola or Lucozade or fruit juice mixed with soda water or lemonade.
- Drink plenty of fluids.
- Try salty foods. Ginger flavoured foods can also help.
- Drink through a straw.
- Keep away from the smell of cooking.
- Wear loose clothing.
- Have plenty of fresh air in your room.
- Try to go for a walk before meals.

**Diarrhoea:**
- Eat light, easily digested foods such as chicken, fish and milk puddings.
- Drink plenty but not with meals; don’t become dehydrated.
- No fatty foods.
- Keep off high fibre foods for a while, eg bran, peas, beans.
- Don’t have very hot or cold foods and drinks.
- Eat little and often.
- If it persists seek medical advice.

**FOOD SUPPLEMENTS**

These can be helpful if you need extra nourishment. There are many different ones to give you extra energy, protein, vitamins and minerals. They come as powders or liquids, to be taken as drinks or added to food and drinks or used in cooking. Some are readily available at chemists but more concentrated ones can be prescribed for certain conditions; a selection of these is listed below. The dietitian at your hospital is the best person to advise on the product most suitable for you and if you have a prescribed supplement it is important that the dietitian should monitor your progress. Ideas for using supplements are given in the recipe section and manufacturers also supply recipe leaflets for their products. If you are having supplements prescribed ask your GP to write “Variety of flavours” on the prescription form - the pharmacy can order a mixture of items for you to try.

**Complete Food Supplements:**
These are high in protein and calories and are nutritionally complete, including vitamins and minerals. They can be taken as drinks between meals or in place of a meal if you cannot manage food and can also be used in cooking. Cartons of sweet and fruit based supplements can be frozen and eaten as ice-cream or sorbets.
**Powders:**
Build up and Complan - on sale at chemists - in a range of flavours, sweet and savoury.

**Liquids:**
- Clinutren 1.5/1.5 Fibre/Fruit/ISO – sweet/fruit flavours
- Enrich and Enrich Plus – sweet/fruit flavours
- Ensure and Ensure Plus – sweet/fruit/savoury flavours and yoghurt style
- Fortifresh and Fortimel – sweet/fruit flavours
- Fortisip Bottle/Protein – sweet/fruit flavours
- Fortisip Multifibre – includes some savoury flavours
- Fresubin Original/Energy/Energy Fibre/Protein Energy Drink – sweet/fruit flavours
- Nutriplus
- Resource Shake/Protein Extra – sweet/fruit flavours

**Puddings:**
- Clinutren Dessert – caramel/chocolate/peach/vanilla
- Formance – vanilla/butterscotch
- Forticreme – vanilla/chocolate/coffee/banana/forest fruit
- Resource Energy Dessert – caramel/chocolate/vanilla

**ENERGY SUPPLEMENTS**
In liquid or powder form these are an easy way to get extra energy but they are not nutritionally complete. They may be obtained on prescription.

**Liquids (various flavours):**
- Calogen – sweet/fruit flavours
- Maxijul – fruit flavours
- Polycal – orange/neutral
- Enlive Plus, Fortijuice, Provide Xtra and Resource Fruit Flavour Drink – fruit juice based and fat free. They maybe preferred to milk based supplements but provide fewer calories.

**Powders:**
- Resource Benefiber - can help with both constipation and diarrhoea.
- Maxijul
- Polycal
- Calshake, Enshake and Scandishake - flavoured - mix with fresh milk

**Fortified Milk:**
A useful supplement easily made at home, used like ordinary milk but giving more protein and energy. Mix 4 tablespoons of milk powder with a pint of milk (easiest to do in a blender).

**SOFT NUTRITIOUS FOODS AND SOME WAYS TO TAKE THEM**
- Milk puddings • Shepherd’s pie
- Soufflés • Pasta dishes (*liquidise, if necessary, after cooking*)
- Porridge • Braised meat
- Pancakes • Lentils
• Egg custard  • Grated cheese
• Mousses  • Cottage cheese
• Full fat yoghurt  • Cream cheese
• Milk jelly  • Dahl
• Creme caramel  • Taramasalata
• Fromage frais  • Moussaka
• Milk shakes  • Peanut butter
• Omelettes  • Avocado
• Scrambled eggs  • Hummus

• Fruit mashed or blended - stewed apple, banana, strawberries, melon, ripe pears etc
• Cartons of fresh stock can be bought in supermarkets - more nutritious than stock cubes.
• Angel Delight made with fortified milk and served with fruit, eg butterscotch flavour with stewed apple or chocolate with mashed banana.
• Use milk, cream, fruit juice, sauces, stock or gravy as appropriate to soften the consistency of foods.
• Many soup recipes are suitable as long as a processor/blender is used.
• There are many varieties of prepared sauces, in tins, jars or packets. Soups, especially if condensed, also make good sauces.
• Poached or flaked fish in sauce.
• Grilled bacon or ham, processed, in scrambled eggs or omelettes.
• Instant mashed potato, enriched with butter or cheese, for when the family is having chips or roast potatoes.
• Fish pates - salmon, tuna, smoked mackerel, made softer with milk, cream, mayonnaise or stock.
• Herbs to add flavour - eg thyme, basil, oregano, parsley, mint, chives.
• Cranberry sauce, red currant jelly and chutney to add piquancy to meat dishes
• Pasta is very good - liquidise, if necessary, after cooking

RECIPEs

Recipes using Food Supplements

**Complan Soup**
1 tin or packet of soup 3 heaped dessertspoons natural flavour Complan
Heat enough soup for one serving, following the instructions on the tin or packet. Mix Complan with a little cold water to make a smooth paste. Remove soup from heat and slowly stir in the Complan.

**Complan Angel Delight**
1 packet Angel Delight 3 heaped dessertspoons natural flavour Complan ½ pint cold water
Mix Complan with a little water to make a thin cream, then add the remaining water. Sprinkle in the dessert powder arid whisk briskly.
**Complan Jelly Cream**

1 pint packet jelly
4 heaped dessertspoons Complan (a flavour that blends with the jelly)
Make the jelly in the usual way and leave until cold but not set. Mix Complan with a little cold jelly to make a smooth cream. Blend mixture into jelly, stirring slowly all the time. Pour into four individual moulds or dishes and leave to set.

**Build-Up Milk Jelly**

1 sachet strawberry Build-Up 1 packet strawberry jelly
½ pint milk or fortified milk or vanilla Ensure
Dissolve jelly in a little boiling water and make up to ½ pint with cold water. Mix Build Up with the milk. When jelly is cold but not set, stir it slowly into the Build-Up. Pour into individual dishes or moulds and leave to set.

*Alternative flavours.* Vanilla Build-Up with various jelly flavours, or chocolate

**Build-Up Yoghurt**

½ sachet Build-Up 5oz carton natural full-fat yoghurt
You may find Build-Up too sweet: mixing it with plain yoghurt gives it a much sharper flavour.

**Ensure instant Soup**

1 can Ensure 1 packet instant soup mix (eg Cup-A-Soup)
Heat Ensure but do not boil, add soup mix, stir well, blend and serve.

**Ensure Banana Shake**

1 banana 1 can chilled Ensure
Peel and slice the banana. Place in blender, add Ensure and blend until smooth.

**Chocolate Diablo**

1 tablespoon drinking chocolate 1 teaspoon instant coffee
1 can Ensure Pinch cinnamon
Mix chocolate, coffee and cinnamon, add 2oz Ensure and stir until smoothly mixed. Stir in the rest of the Ensure and heat to required temperature, stirring all the time. Do not boil.

*Alternatively,* use chilled Ensure, mix as before and blend (with a scoop of ice cream if liked).

**Soups**

**Stilton Cheese Soup**

2oz butter 1 onion, finely chopped
2 sticks celery, finely chopped 1½oz flour
5 tablespoons white wine 1 pints chicken stock
½ pint milk 4oz blue Stilton cheese, crumbled
2oz Cheddar cheese, grated Salt and freshly ground pepper
4 tablespoons double cream
Melt butter in a saucepan, add vegetables and fry gently for 5 minutes. Stir in flour and cook for 1 minute. Remove from heat and stir in the wine and stock; return to heat and bring to boil; simmer for 30 minutes. Add milk and cheese, stirring constantly. Season, stir in cream, liquidise, reheat but do not boil.
Smoked Fish Chowder
1lb smoked haddock fillet 8oz potatoes, finely chopped
2 medium onions, finely chopped 6oz carrots, finely chopped
2oz butter 2 level tablespoons flour
¼ pint single cream Salt and freshly ground pepper
Simmer the fish in 2 pints water for 10 minutes until tender; drain and flake coarsely, discarding the skin and bones. Sauté onion in the butter until soft then stir in the flour; gradually add the strained fish stock and bring to the boil, stirring. Add potatoes and carrots, simmer for about 10 minutes until tender, stir in flaked fish and cream, season well; liquidise and sieve if necessary; reheat but do not boil.

Chicken and Vegetable Soup
2 onions ½lb carrots
2 turnips ¼lb mushrooms
A few frozen peas and any other vegetables in season
2oz butter 1½ pints chicken stock
Salt and freshly ground pepper Mixed herbs
Finely chop vegetables; melt butter in saucepan and sauté onions until soft; add the other vegetables and chicken stock; bring to the boil and simmer until vegetables are soft; season, liquidise, sieve and reheat.

Cream of Mushroom Soup
½lb mushrooms, sliced ¾ pint chicken stock
1 small onion, chopped 1oz butter
1oz flour ¾ pint milk
2 tablespoons cream Salt and freshly ground pepper
Place the mushrooms in a pan with the onion and stock, bring to the boil and simmer for 20 minutes until tender; liquidise. Melt butter in a pan, add the flour and cook for 1 minute; gradually blend in the milk and then the prepared mushroom purée and season to taste; bring to the boil and simmer for 5-10 minutes. Just before serving stir in the cream.

Main Dishes

Cheese Pudding Serves 4
½ pint milk Knob butter or margarine
3oz fresh breadcrumbs 4oz grated cheese
3 eggs Salt and pepper
Pinch dry mustard
Grease a 2 pint baking dish. Put breadcrumbs into a bowl. Heat the milk and butter until just boiling and pour over the breadcrumbs; leave to cool for a few minutes. Separate the eggs; mix the yolks with the cheese and seasoning, and stir into the breadcrumbs. Whisk the egg whites until stiff and fold into the cheese mixture. Pour into the baking dish and bake at 375°F (190°C, Reg 5) until risen and brown (30-40 minutes). Serve at once.
Cheesy Tuna Casserole  Serves 4
7oz tin tuna  1 tablespoon chopped onion
2 eggs  8oz cottage cheese
2oz fresh breadcrumbs  Salt and pepper
Drain and flake the tuna; mix with cottage cheese, onion, breadcrumbs and seasoning. Beat the eggs and mix well with the fish mixture. Turn into a greased 1 pint casserole dish and bake at 350°F (180°C, Reg 4) until set (30-40 minutes).

Fish Mousse  Serves 2
4oz tinned salmon, tuna or kipper fillets
3 fluid oz whipping cream  2 tablespoons mayonnaise
A little lemon juice  Salt and pepper
2 teaspoons gelatine
Dissolve the gelatine in a little hot water. Flake the fish, removing any bones or skin; blend if necessary. Mix well with the mayonnaise and lemon juice and season to taste. Stir in the gelatine. Whip the cream until it forms peaks, and fold into the fish mixture. Pour into a serving dish and place in a fridge until set.

Ham Custard  Serves 2
4oz cooked ham, minced or chopped
½ pint milk  2 eggs
Salt and pepper
Grease a 1 pint baking dish and place the ham in it. Beat eggs, milk and seasoning and pour over the ham. Stand the dish in a shallow pan of hot water and bake at 325°F (170°C, Reg 3) until set (40-50 minutes).
Variations; you can replace the ham with cooked chicken, grated cheese, or flaked cooked fish, and cooked vegetables may also be added.

Macaroni Cheese  Serves 2
4oz macaroni (or cut spaghetti or other small pasta)
½ pint cheese sauce (see Sauces)  1oz grated cheese
Cook the macaroni in lightly salted boiling water until just tender; drain and tip into a baking dish. Pour the cheese sauce over and sprinkle with grated cheese. Bake at 375°F (190°C, Reg 5) until brown (20-30 minutes).
Variations; minced ham or chicken can be added, or vegetables such as sweetcorn or peas.

Chicken Supreme  Serves 1
About 3oz cooked minced chicken  Tinned condensed mushroom soup
Mix together and heat gently in a saucepan. Serve with rice.
Variations; chopped cooked vegetables can be added or other kinds of meat or fish can be combined with different varieties of condensed soup.
**Puddings**

*French Rice Pudding*  
Serves 3-4  
2oz ground rice  
2oz sugar  
1 pint fort milk or milk and vanilla  
1 egg  
Heat milk and sugar in a saucepan until almost boiling; sprinkle in the ground rice, stirring well until just boiling. Simmer until rice is tender (3-4 minutes) and allow to cool slightly. Separate the egg and beat the yolk into the rice. Whisk the egg white and fold into the rice. Pour into a greased pie dish and stand it in a shallow pan of hot water. Bake at 350°F (180°C, Reg 4) until well risen (about 20 minutes).

*Apricot Fool*  
Serves 3-4  
12-16 oz cooked or tinned apricots (or other fruit)  
1/2 pint high protein custard (see Sauces)  
Sugar to taste  
Drain the fruit well and sieve or blend to make a thick purée; sweeten to taste. Make the custard and whisk with the fruit. Pour into individual serving dishes. Chill, and serve with cream.

*Quick Milk Pudding*  
Serves 3-4  
2oz semolina, ground rice or flaked rice  
2oz sugar  
1 pint fort milk or milk and vanilla  
Heat milk and sugar until almost boiling. Sprinkle in the cereal, stirring well until just boiling. Simmer until cooked (3-4 minutes). Serve with jam, honey or golden syrup.

*Baked Egg Custard*  
Serves 4  
1 pint fort 4 milk  
3 eggs  
1oz sugar  
Grated nutmeg (optional)  
Heat the milk until almost boiling. Beat the eggs and sugar together and pour the hot milk slowly over them, stirring well. Pour into a greased 1 1/2 pint baking dish and sprinkle nutmeg on the top. Stand the dish in a shallow pan of hot water and bake at 325°F (170°C, Reg 3) until set (30-40 minutes). The finely grated rind of an orange can be added to the custard mixture if liked.

**Sauces**  
These recipes use fortified milk - see section on Supplements

*High Protein White Sauce*  
1 pint fort milk  
1 1/2oz butter or margarine  
1 1/2 plain flour  
Melt the fat in a saucepan; add the flour and stir well. Cook gently for 1-2 minutes and remove from heat. Add the milk a little at a time, stirring well to make a smooth sauce. Return to heat, stir until sauce boils. For a savoury sauce season with salt and pepper; for a sweet sauce add sugar to taste.  
High Protein Custard
1 pint fort milk 2 tablespoons custard powder
1-2 tablespoons sugar
Mix sugar and custard powder to a smooth paste with a little cold milk. Heat the rest of the milk until just boiling. Pour onto the custard powder mixture, stirring well. Return to pan, stir until boiling and simmer for 1-2 minutes, stirring all the time.

High Protein Chocolate Sauce
1 pint fortified milk 1-2 oz sugar
1oz cornflour ½oz cocoa powder
Mix sugar, cornflour and cocoa powder to smooth paste with a little cold milk. Heat the rest of the milk until just boiling. Pour onto the cocoa mixture, stirring well. Return to pan, stir until boiling and simmer for 1-2 minutes, stirring all the time.

When You Really Can’t Face Food
You may be able to manage some of these drinks, jellies and frozen desserts. Keep some in the fridge and freezer for days when you don’t feel like eating. Serve them well chilled and take drinks through a straw. You can also buy chilled and frozen desserts to use in the same way or freeze fruit flavoured supplements to make ice-cream or sorbets.

Citrus Cup
Equal quantities of lemon Polycal and orange juice. Mix and serve.

High Protein Milkshake
½ pint fortified milk 1 scoop vanilla ice-cream
Put the ingredients into the blender and blend at low speed for a few seconds. Flavour with Ribena, Crusha syrup or fruit purée; for energy use maple syrup or honey. For iced coffee use a dessertspoon of coffee essence or a teaspoon of instant coffee with sugar to taste, and blend with milk before adding ice cream (vanilla, coffee or chocolate).

Tomato Yoghurt
5oz carton plain yoghurt ¼ pint tomato juice
2oz high energy powder, eg Maxijul or Caloreen
2-3 fluid oz hot water
Dissolve the high energy powder in the hot water; mix all ingredients by hand or in a blender; flavour with Worcestershire sauce, celery salt or just salt and pepper; chill well and serve in a tall glass with a straw.

Yoghurt Cooler
5oz carton fruit yoghurt ¼ pint milk
Mix together by hand or in a blender. Serve in a glass with a straw.

Jelly Whip
1 packet jelly 1 small tin evaporated milk
Chill the tin of milk in the fridge for a few hours. Dissolve jelly in ¾ pint hot water and allow to cool. Whisk evaporated milk until it forms peaks and stir into the cool but not set jelly. Pour into individual dishes and place in the fridge to set.
**Lemon Water Ice**
Grated rind and juice of one lemon  2 oz sugar
2 tablespoons of honey  1 teaspoon of gelatine
½ pint of water
Heat sugar and water together, allow to boil for five minutes. Dissolve gelatine in a little hot water. Mix lemon rind, juice and honey into the hot syrup, add gelatine, stir well. Cool, stirring occasionally, then freeze. When beginning to set at the edges, whisk with a fork, pour into individual dishes and complete freezing.

**Frozen Fruit Mousse**
Best fruits to use: Fresh, tinned or frozen raspberries, strawberries, apricots, peaches, plums, blackcurrants and rhubarb.
¾lb fruit  3-4 oz sugar
½ pint whipping cream or small tin of evaporated milk, chilled
1 teaspoon gelatine
If using firm fresh fruit, stew in a little water until soft; drain and make into a thick purée in the blender or by sieving; add sugar to taste. Dissolve gelatine in a little hot water; stir into the fruit and cool in the fridge. When just beginning to set whisk well. Whip the cream or evaporated milk and fold in the fruit; pour into individual dishes and freeze.

**Companies producing food supplements can be contacted for recipe ideas:**
Abbott  01628 773355  (Ensure, Enlive)
Fresenius  01928594200  (Calshake, Entera, Frebini)
Nestle  0208 6675130  (Caloreen, Clinutren)
Novartis  01403 210211  (Resource, Benefiber)
Nutricia  01225 711801  (Fortifresh, Fortisip, Nutrison, Polycal)
Web site www.nutricia-clinical-care.co.uk
SHS  01512288161  (Maxijul)

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Appendix VIII

Submission from Lymphoedema Support Network:

a. patient stories – lymphoedema secondary to cancer
b. qualitative data analysis
c. quantitative data analysis
Lymphoedema Secondary to Breast Cancer

I was diagnosed with breast cancer in April 2003, aged 41; one month after my father died of cancer, and two days after my son’s 4th birthday. I had initial surgery in July 2003, when I underwent a lumpectomy and a sentinel node biopsy. I was so relieved to have been selected to take part in the sentinel node biopsy trial as I had heard of lymphoedema and didn’t want it to happen to me. Unfortunately, the one node was positive and I had to undergo a full node clearance. As I stated earlier, my son was four and still a ‘little’ boy. Having gone through so much - he asked me on the day that I went into hospital if he might be too late to see me (he’d been at nursery when my dad died). I was determined to be as normal a mum as possible for him. This included still picking him up if he was hurt - what mum wouldn’t. I was still devastated when my arm began to swell, almost a year to the day after my surgery. There was a very long waiting list for the lymphoedema service, so I wasn’t seen until October 2004. As my arm was 12% swollen, I had to have a sleeve. The dreadful colour was as depressing as the diagnosis. I spent several months trying to contact various sleeve manufacturers asking them about availability in different colours to match clothes, only to be dismissed with very curt emails. I’ve now given up for the time being, although do try again every summer, when the sleeve obviously becomes very noticeable and people ask questions like "What have you done to your arm?" The exercises have become a part of my daily life and were so successful at one point that I was told I needn't wear the sleeve unless I was going to be doing some typing etc. Unfortunately, my arm got bigger again and I’ve now been told this is it for life. If cancer wasn’t bad enough, this is a daily reminder. I try to take good care of my arm. When we went on holiday to Majorca, I thought I’d be clever and wear the sleeve at night as a protection against mosquitoes; I didn’t know that they can bite through the material, with the result that I had a lovely case of cellulitis! Thankfully, I got a course of antibiotics easily and have a very sympathetic GP at home who is now happy to prescribe a course of ‘just in case’ antibiotics when we go abroad.

The sleeve and living with lymphoedema have now become a part of me but I would like to think that if there is anything that I can do to support other people living with this condition or to prevent others developing it, I would be happy to do so.

Lymphoedema Secondary to Breast Cancer

During the first week of January 1985, I underwent a lumpectomy to my left breast. The tumour proved to be malignant. After a period of three weeks I had radiotherapy for eight weeks. Two treatments a week, alternating with three treatments a week. I had no after effects of the treatment apart from feeling a little nauseous and tired towards the end the course.

Two and a half years ago, some twenty one years after the radiotherapy, I noticed that my hand had become swollen - quite alarmingly. As it was during the hot weather in June, I assumed I had been bitten by an insect. After two or three days no improvement had been made, I therefore consulted my GP. She thought I had been bitten and prescribed anti-histamines which I was already taking for hay fever.
After a further two weeks, the hand seemed to be worse some days than others. I consulted another GP in the practice who immediately exclaimed "Oh, you've got lymphoedema" and made an appointment for me to attend the lymphoedema clinic at the local hospital.

I was treated very sympathetically at the clinic and given a compression arm sleeve to wear. I attend the clinic every six months and the measurements of my arm still vary quite a lot.

About 18 months ago I had a course of the Bowen technique, which is a form of very gentle massage. Whether it was coincidence or not I don't know, but the arm measurement dropped quite a lot. I would like to have continued with the massage but it is rather expensive at £30 per session and I was recommended to have three. I do massage the neck and chest part of my body as suggested by the lymphoedema nurse at the clinic I attend but cannot be sure that this has been beneficial.

**Lymphoedema Secondary to Breast Cancer**

I was first diagnosed with breast cancer in 2000 and had a lumpectomy and lymph nodes removed. After I was discharged, I had a build up of fluid under the arm which was drained off by one of the breast care nurses at the hospital. I underwent 3 weeks of radiotherapy and was then back under the care of the breast care unit. I recovered well with no more problems with my arm at all.

In 2002 I was diagnosed with cancer in my right breast (unfortunately, by this time, I had tested positive with the BRCA 1 gene). I had lost a sister to ovarian cancer and a younger sister had undergone surgery for breast cancer, so the advice of the Consultant, because of the family history, was to reduce my risk as much as possible of a reoccurrence, by having bi-lateral surgery, which after some consideration, I decided was the safest option. I had radiotherapy and 6 months course of chemotherapy. A Hickman Line was fitted into my chest so that the drugs, blood tests etc. could be carried out. The fact that I had lost lymph nodes on both sides was the factor for that decision. I was doing as well as could be expected until about 3 months into my chemo when I was hospitalised due to a very low blood count and infection. No one on the unit I was on seemed to know much about lymphoedema and were unable to take blood pressure samples through the Hickman Line as they were not qualified to do so. I expressed my concerns about this and blood pressure being taken from my left arm but was told it was important that they do this and I was made to feel I was making a fuss.

The left arm was used because I had lymph nodes removed from that side first. By December I was unable to wear my rings and the hand had become swollen. I was referred to the lymphoedema clinic at the local hospice and it was confirmed that I had secondary lymphoedema of the left hand and arm. I was supplied with a compression sleeve and glove and shown simple lymphatic drainage massage.

To say that I was devastated would be an understatement.
Because my arm had remained fairly stable and I was coping with skin care etc. I was discharged in October 2005 and just needed to contact them for replacement sleeves and gloves. No problems again with the right hand until April 2006 when the hand started to show signs of swelling. The only procedure had been a blood pressure reading at my GP surgery, they do not have a cuff long enough to go around the leg and so I really had no choice. Once again, I was back at the lymphoedema clinic and diagnosed with secondary lymphoedema of the right hand and arm, so now I have the matching pair! I attend the clinic every 4 months and they are most supportive and caring.

I feel both upset and frustrated by my experience as I took so much care of myself after all of my surgery and did all of the things I was advised to do. It has been my experience that at most levels there appears to be a complete lack of knowledge about lymphoedema, its causes and implications, the factors and effects of this condition.

Before surgery, I was handed leaflets explaining about the need for care of the skin, exercises and other tips to avoid this occurring. I feel it's the Health Service that needs the information more than the patients.

I hate the summer time when I wear less clothing and I do know how lucky I am to be dealing with secondary and not primary lymphoedema, but after battling cancer twice, it takes some dealing with. I fully support your campaigns to raise awareness of this condition which can be so debilitating. It needs recognising as a very serious condition and bringing into the public eye

**Lymphoedema Secondary to Gynaecological Cancer**

After being diagnosed with cervical cancer in April 1988 I underwent a 'Vertheims' hysterectomy in June of that year. The specialist explained that due to my age (only 34) my ovaries would be left in place if they were found to be clear, but that the major lymph nodes in my pelvis would have to be removed as the cancer could travel through these to other parts of my body.

After the operation and a three week stay in hospital, I was eventually given the all clear and returned home to recover. My treatment whilst in hospital was excellent, but at no time was lymphoedema mentioned or even the possibility of it occurring.

One day, approximately eighteen months later, I began to feel extremely ill with a severe headache and nausea which lasted for a couple of days. I also noticed a burning rash had appeared around my groin which spread down my left leg. I immediately visited my doctor who was completely baffled and sent me to the local hospital where a skin sample was taken to check for cellulitis, by this time my leg had started to swell considerably and I was becoming increasingly worried about what this may be. I later got the results from the skin sample which came back negative.

Over the next 12 years I had regular check-ups at my local hospital and on each occasion I asked the doctors about my leg. No-one seemed to know what was wrong and one doctor actually told me to think myself lucky I was alive, never mind complaining about my leg!
Only one specialist I saw attempted to do anything about it by offering me physiotherapy and suggested I had a few sessions on the exercise bike in the hospital gym.

Throughout all this I continued to work full time and tried to cope with my swollen leg by wearing trousers when I could find a pair that fitted my swollen leg. I also bought the strongest support tights I could find, thinking these would help, which I wore with skirts. There were some days when my foot was so swollen I could not get shoes on at all. After searching the internet on my brother's computer I found out a great deal more about the condition and the details for the LSN, which I immediately joined.

After moving home in 2000 I registered with a new GP and mentioned my lymphoedema to her. She immediately referred me to the Macmillan unit at the local hospital where I have been receiving treatment for the past few years. I was given several sessions of MLD [Manual Lymphatic Drainage] and this, together with a compression stocking has made an astonishing difference to my leg.

I know there is no 'cure' for lymphoedema but knowing that there are people out there who understand the condition helps me to cope. I am still working full time, go on long walks whenever I am able and try to keep my weight down. It has taken me around 14 years to get treatment despite me constantly pestering the doctors on the visits to hospital, none of whom seemed to know what it was, let alone how to treat it. I now know a great deal more about the condition but most of this I have had to find out for myself.

All I can say, is thank goodness for my new GP!

**Lymphoedema Secondary to Gynaecological Cancer**

It's hard to believe that only three years ago, lymphoedema was just a medical term, something I needed to be aware of when anything needed lifting, or at hospital appointments when needles loomed, but it played no significant part in my everyday life. I could wear short skirts, high heels and have bare legs in summer. Sadly those days are gone and now exercise, massage and wearing compression tights are part of my daily routine.

When first diagnosed with cancer I felt, like many others, that life couldn't get much worse - but it did! Learning that I had a chronic condition that couldn't be treated by surgery or drugs and the growing realisation that I was on my own in dealing with it, was devastating. The pathos in the slogan "Lymphoedema - because cancer is not enough" neatly summarised my feelings.

In 2001 I had a bi-lateral mastectomy, with the removal of lymph nodes on each side. The breast care nurses went to considerable trouble to warn me of the risks of developing lymphoedema and gave advice about avoiding trauma to the arms. Fortunately, I did not develop any swelling although it was only later that I understood the life-long nature of the risk.
Two years later, I was diagnosed with endometrial cancer of the womb which necessitated a hysterectomy, the removal of lymph nodes from the abdomen and a course of radiotherapy. The support nurse talked me through what I might expect following radiation. We discussed the effect on my bladder, my bowels and my sex life, but no mention was ever made of lymphoedema. The first indication I had that something was wrong was when, part way through the course of radiotherapy, my abdomen and legs swelled alarmingly and I was in considerable pain. I was admitted to the colorectal ward of a local hospital where a CT scan revealed a large lymph cyst in my abdomen which, when drained contained almost two litres of fluid. Again, no one mentioned the possibility of lymphoedema. After ten days the swelling disappeared and I was able to complete the radiotherapy.

I was keen for my life to return to normal after all this, but as soon as I resumed work, my legs and groin began to swell. Each morning everything was fine, but by midday my left leg was so heavy I felt as though I wanted to 'unhinge' it and carry it over my arm. Fortunately, on my last visit to the hospital, where I was being treated for breast reconstruction, I had picked up a booklet about lymphoedema and I began to read more about the condition. Until this point I had associated it solely with the arms and had not heard of it affecting other parts of the body. In view of what I have learned since, that now seems incredibly naïve.

My worst fears were confirmed when I saw the oncologist who said it 'probably' was lymphoedema, but it would 'settle down' in a few weeks. Meanwhile, I should buy Marks & Spencer support tights (which I had already done) and sit with my feet up as much as possible (not very practical for a busy schoolteacher!) I had read about MLD but was told that it was only available privately and because the swelling was in my legs rather than my arms, the NHS could offer me nothing more.

Each day the swelling in my legs and groin worsened and became more painful. I felt depressed and utterly helpless. Having had my breasts, womb and ovaries removed, my legs seemed to be the last vestige of femininity that remained and they were becoming increasingly ugly. Simple things which I had always taken for granted now became an issue. I could no longer wear heels; brisk walking or running were impossible; and sitting for any length of time - at the computer, in the car, at the theatre or in a restaurant - caused increased swelling. Unlike my earlier experiences with cancer, when I had always had support via a telephone line and could discuss my worries with a qualified practitioner, I was now on my own.

In desperation, I rang a local lymphoedema clinic, which offers an excellent range of support treatments to cancer patients, including teaching massage techniques to breast cancer patients, but as the lymphoedema was not in my arms they were not able to see me. My next thought was to contact an MLD therapist. The list I obtained from the Internet showed several in my area and I spoke to some of them by telephone. They were all sympathetic and outlined the different treatments on offer, but I was in a dilemma over which to choose and ended up feeling confused.
Luckily, I found details of the LSN in the back of the handbook published by my hospital and rang the helpline - not very hopeful, I must admit - to see if they could offer any advice. I spoke to a very sympathetic lady, who explained how she managed her own condition and told me of a clinic only 15 miles from my home, which may be able to help. Her re-assurance and positive approach gave me hope that something could be done.

Although the clinic dealt with breast cancer patients, the two wonderful nurses who run it offered to help and were interested in transferring their expertise in treating arms, to other parts of the body. They offered practical advice, explained some simple massage techniques and gave me a contact number to use if I became worried. I felt like hugging them! I went three times to the clinic and their support made such a difference.

Some time later, during a follow up appointment at my hospital, I mentioned my concerns about lymphoedema to my consultant. He told me about the work of Professor Mortimer and referred me to the clinic at the Marsden. Shortly after this, I met two of their lymphoedema specialist practitioners and oh, the relief in talking to people who knew what to do about my swollen legs! They used computer imaging to assess the extent of my lymphoedema; explained the importance of exercise and daily care; supplied me with compression tights; and later offered me a course of MLD. I now attend twice yearly for regular monitoring.

The swelling and pain have reduced considerably and my lymphoedema is now manageable. I’ve installed a tread mill at home so that I can walk each day whatever the weather, taken up Pilates and even, on a few occasions, I’ve been able to wear high heels. Although I have had to make adjustments to my life and need to take care with certain activities, lymphoedema has not stopped me doing the things I’ve wanted to do over the past 2 years - life is good again!

I am fortunate to attend such an excellent clinic and the 80 mile round trip is certainly worthwhile, but it would have saved me a great deal of anguish if information and support had been made available by my local PCT, which serves a population of 360,000. There must be many others in the area needing help with lymphoedema in the legs or abdomen and feeling as desperate and isolated as I did. In all other respects the cancer care I’ve received over the past five years has been superb. The priority was obviously to treat my two cancers, but it became increasingly clear to me that many doctors and consultants have little or no understanding of lymphoedema and the impact it has on the quality of life. Only when medical training gives lymphoedema the status it deserves can we hope for improved services.

**Lymphoedema Secondary to Gynaecological Cancer**

In December 1998 I had to have a full hysterectomy due to advanced cancerous cells of the womb, also some lymph glands were removed. I was fine until a year and a half later when my feet started to swell up and become misshapen. It was during the summer so we put it down to being warm and standing up in my shop.
I went to see my GP who tested my heart etc. and then gave me a support knee sock which, after maybe two weeks, did no good at all. Plus, now my leg had started to swell and became all lumps and bumps and very achy. I then went back to see a consultant at the hospital who thought it might be a leg infection so I was given a course of antibiotics. Two weeks later, it was no better but much more painful and swollen. The hospital then sent me for a scan and tests thinking it might be a DVT, but nothing there. Just before Christmas 2000, I was told it was lymphoedema, which I had never heard of. As it happens, a lymphoedema nurse had just been assigned to my hospital, so I was virtually her first patient.

She was marvellous and gave me some hope that eventually somebody could do something for me. She measured my leg and showed me how to massage it and ordered some support stockings. Slowly but surely my leg started to get some shape back and the swelling went down quite a lot. My leg is massaged every single night with Diprobase cream by my husband and I wear the stockings every day. It still aches but is much more manageable now.

It is a forever job but well worth it and I’m supplied with stockings twice a year, for which I am very grateful. I recently had breast cancer and lymph glands were also removed so I’m now massaging my arm in a preventative measure, hoping no swelling will occur.

There must be many, many people suffering from lymphoedema and no help available for them as yet; it is a very sad situation. I count myself lucky for having my treatment.

**Lymphoedema Secondary to Melanoma**

When I noticed a mole above my knee on the inside of my leg, as I had private medical insurance, my GP referred me to a skin specialist who has been brilliant all the way through. He subsequently removed the mole at a private outpatient clinic. When I received the results of this surgery, they showed cancer. I was referred to a plastic surgeon and put on the NHS list as he was unable to fit me in on his private list. A wider incision of the mole site was taken and also the lead lymph node in my groin area. The results of this showed traces of cancerous cells. Two weeks later, I had all the lymph nodes removed in my left groin via a groin dissection. On the morning of my surgery to remove all the lymph nodes, I was told by the registrar "you will probably have to wear a support on your leg the rest of your life as a result of swelling".

I went backwards and forwards weekly after surgery to the NHS clinic where they were draining the groin area. I was going on holiday six weeks later and just before my holiday a senior nurse at the plastic surgeon's clinic measured me for a made-to-measure support. I did not receive this for nearly three weeks.

I did not have to have any chemotherapy or radiotherapy and I was not seen by an oncologist. I am now seen every three months by the skin specialist at a private clinic.
I tried to wear the support, but to be honest, it was horrendous. It was uncomfortable, it slipped down when I was walking, went into a crease at the back of my knee and at the ankle, and I was forever pulling at it and tugging at it. I tried to contact the plastic surgeon's senior nurse about my problems but could not contact her and found the clinic totally impersonal and useless. As the weather got hotter and the support became even more unbearable, I got to the stage of stopping wearing it altogether.

I hunted on the internet to try to find a source to buy my own support stocking. I bought a pair of lycra shorts from a website that I found - which were comfortable - cost in excess of £50 - but did not stop the swelling. By this time, I had found information from the LSN website and a contact nearby, who kindly gave me the names of suppliers of support stockings locally and she also enquired if I had been referred to a lymphoedema clinic - I hadn't and didn't know this even existed.

I went back to my GP (whom I had never consulted prior to this) and asked to be referred to a clinic. I was seen by a Physiotherapist at the lymphoedema service and within minutes of meeting her, she was showing me various types of support stockings that she could source and gave me information about the LSN and their fact sheets. She measured me again and within one week I had a new support to wear which is brilliant, I can wear it all day, seven days a week. I was given information about wet shaving my legs, cuts and grazes when gardening, the effects of the sun, care of the skin - all new to me and something I had never considered before. I received two garments on the NHS and I am due to go away on a long holiday next year; when I enquired if I could buy a third garment myself, I was quoted £54 for one stocking! I joined the LSN and purchased the video about self massage techniques, which was much easier to follow than what the Physiotherapist had showed me.

I don’t know if the lack of information given to me was due to being under the plastic surgery unit, not having a cancer nurse, or not having to see an oncologist. Nor was I ever referred to a lymphoedema service. Given the increase in Melanomas that is constantly reported in the press, I cannot be alone in receiving no backup - no advice - no literature - and having to source everything for myself.

I feel that the whole attitude was "you are cancer free, get on with life". I am not the sort of person to get depressed and so I never sat and felt sorry for myself and did not give up by thinking "this is it for the rest of my days". I am in my late forties and thank my lucky stars that I have been given the all clear. I am fit and healthy now and I don't let my lymphoedema stop me from what I am doing. But it would have been so easy to give up if I was that way inclined.

I only hope that the LSN can find a way to ensure that all patients receive the valuable information that it can source for them. I cannot see that it would be impossible, surely just for the hospital to give that first form of contact to the LSN to ensure that anyone affected in this way is given support and information. I feel that the lack of information provided was a major oversight at the time of my surgery and immediately after. If I had had more information - or simply a card giving contact details of the LSN - I would not have struggled for so long.
Qualitative data themes analysis

FACT SHEETS

In general the fact sheets are thought to be helpful, clearly written and informative and a useful reference to keep, give to GP, schools other family members. Some members were obviously not aware of the full range of fact sheets that are available. In particular skincare, travel and flying, compression garments, preventing/treating cellulitis/ulcers, preventing lymphoedema, nutrition, MLD practitioners.

New fact sheets suggested
- Pain control
- Primary lymphoedema – specific advice re genetics, recognition and support.
- Alternative therapies – reflexology, acupuncture/acupressure, herbalists, diet
- How to obtain travel insurance
- Specific exercises that can help - rather than recreational exercise
- Stockists for clothes/shoes – particularly fashionable ones for younger members
- Kinesiotaping
- Bra fitting for breast oedema
- Financial support – DLA, Attendance allowance, disabled car stickers
- Entitlements to treatment and how to access what is available
- Lipoedema
- Coping with hot weather
- Lymphoedema and how it impacts with other conditions, diabetes, arthritis, MS
- Lymphoedema in pregnancy

LSN VIDEO

The video was appreciated by those who had bought it – very few criticisms 2 of which mentioned the cost and three said it was a bit depressing. Otherwise the positive feedback fell into the following categories

- Clear and easy to follow
- Good to show others, family etc
- Useful for health professionals to show patients
- Useful for support groups to share
- Good to keep as a reference to watch repeatedly
- Better than written information as easier to follow
- Better than individual demonstration as can be looked at again and again
- Helpful to see hosiery being put on
- Exercises, SLD very useful
- Very encouraging as it showed how real people cope with lymphoedema.
Lymphline

*Widely appreciated with a large number of comments.*

Positive comments
- Updates on research
- Information on treatments
- Updates on campaigns
- Patients stories and tips/letters
- Enjoy humour especially Jed’s articles
- Reduces feelings of isolation
- Useful to pass on to others, families, GPs, HCAs

Suggestions for improvements
- More articles on primary lymphoedema
- More articles for the younger members and children
- More frequent issues
- More patient stories/hints on coping
- Articles on managing in warmer weather, natural/alternative therapies, research at home and abroad
- More on the emotional, psychological impact of lymphoedema
- Include regularly details of all support groups, stockists of clothes/shoes, MLD practitioners, what fact sheets are available.
- Information on the different types of compression garments, which are the best/cheapest, most fashionable, best tensions and where to get them from.
- Several members mentioned that at time the articles where quite heavy and technical and went over their heads.

Help line

*Relatively few comments with some members not knowing it existed. Those who did comment were almost universally positive Comments can be categorised as follows*

- Provided information on where to get treatment, garments, glue, shoes, waking poles, and referral.
- Provided general information and support
- Staff helpful and reassuring, sympathetic
- Good to talk to somebody who knows what they are talking about
- Prompt response, very professional
Web site

Relatively few comments although it should be noted that this is the first point of contact for many members. The comments received where generally positive.

- Good links to research and MLD therapists
- Often point of first contact
- Good information, easy to navigate.

Negative comments
- A bit boring/uninspiring
- Needs to be updated more regularly

Suggestions
- A chat room
- Patient stories
- More tips/hints about coping with lymphoedema
- Could fact sheets be downloadable
- More information on clothing, shoes.
- More information for young people

Letters/emails

Very few comments: - several of which were raising issues about unanswered emails/letters – all investigated and answered no change to policy suggested. Several positive comments which can be categorised as follows.

- A good response – Anita and Barbara particularly mentioned
- Good and helpful responses
- Brilliant

General Information

A vast amount of data including many personal stories and experiences. The comments can be categorised as follows.

- Thanks to the LSN for help and support
- Appreciation of the work of the LSN
- GP’s a large volume of comments highlighting particular areas of concern for members.
  Lack of recognition of the condition leading to delays in diagnosis/treatment
  Lack of knowledge about what treatment available
  Lack of empathy ranging to accusations of mental cruelty (I was made to feel the lymphoedema was due to greed and stupidity)
  Wrong hosiery supplied.
- All health care professionals including hospital consultants and nurses ignorant of risks of taking blood/ BP reading from affected limbs.
• Service provision
  Post code lottery
  Inequity between cancer related and primary lymphoedema
  Lack of local services
  Lack of services generally
• Patients not informed of risks prior to surgery/treatment
• Thanks to individual therapists/clinics
• Successes of individual treatments
• Offers of individual skills – have been transferred to member information

Suggestions for LSN service improvements
• Use media e.g. documentary on TV/soap, magazine articles
• Make leaflets more available at hospitals
• Produce cellulitis treatment fact sheet in other languages for when travelling.
• Arrange subs payment by direct debit/standing order
• Lobby hosiery companies for more attractive compression garments
• Offer will/legacy package
• Subs very low, arrange sliding scale for those on benefits or pensioners
• Medic alert bracelets
• More trading goods to purchase especially at Christmas
• More information on
  Children with lymphoedema
  Access to MLD for non cancer lymphoedema
  Lipoedema
  Where to buy clothes/shoes
  Coping with mobility issues
  Compression garments
• The LSN is very London based several members asked if the AGM could be held outside of London, or if more attention could be given to regions.
Lymphoedema Support Network Patient Questionnaire 2006 Quantative data analysis

Introduction
In September 2006, as part of the Big Lottery Fund project, a 17 question patient questionnaire was sent to all members of the LSN. The purpose of the questionnaire was to garner the views of members on the current services provided and the future direction of the charity. Prior to sending out the questionnaire was redrafted three times based on comments from a selection of members and representatives of the board of trustees.

A total of 3,700 questionnaires were sent out. 945 were returned by the specified date (25.5 %). The questionnaires collected both quantitative and qualitative data, this report deals solely with the qualitative data.

Question 1 – gender

Of the 945 respondents 84 (8.9%) were male, 837 (88.6%) female and 24 (2.5%) did not specify.

Question 2 – Age

Of the 945 respondents 7 (0.7%) were below 18 years; 13 (1.4%) were between 19-30 years; 60 (6.4%) were between 31-45 years; 435 (46%) were between 46-65 years; 355 (37.6%) were between 66-79 years and 75 (7.9%) were over 80 years old.
Question 3 – post code
Completed questionnaires were received from 123 (93.2%) of the 132 UK postal code areas. Those areas not represented were the Outer Hebrides, Jersey, Kirkwall, Llandrindod, Sunderland, Tweedale, Wigan and the Shetlands. Also represented are Spain and the Netherlands.

Question 4 – Site of lymphoedema
Of the 945 respondents the following sites were identified (it should be remembered that some members have multiple sites).

<table>
<thead>
<tr>
<th>Site</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right hand/arm</td>
<td>233</td>
<td>24.6%</td>
</tr>
<tr>
<td>Left hand/arm</td>
<td>230</td>
<td>24.34%</td>
</tr>
<tr>
<td>Right leg/foot</td>
<td>374</td>
<td>39.6%</td>
</tr>
<tr>
<td>Left leg/foot</td>
<td>504</td>
<td>53.3%</td>
</tr>
<tr>
<td>Trunk/breast</td>
<td>87</td>
<td>9.21%</td>
</tr>
<tr>
<td>Head/face/neck</td>
<td>12</td>
<td>1.3%</td>
</tr>
<tr>
<td>Genital</td>
<td>42</td>
<td>4.5%</td>
</tr>
<tr>
<td>Not specified</td>
<td>2</td>
<td>0.2%</td>
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<tr>
<td>Lymphoedema</td>
<td>2</td>
<td>0.2%</td>
</tr>
<tr>
<td>NA/Therapist</td>
<td>5</td>
<td>0.5%</td>
</tr>
</tbody>
</table>
**Question 5 – Time with lymphoedema**

Of the 945 respondents 145 (15.4%) had the condition for less than 2 years; 217 (23%) for between 2-5 years; 200 (21.2%) for between 6-10 years and 373 (39.5%) for more than 10 years.

![Bar chart showing time with lymphoedema](image)

**Question 6 – Causes of lymphoedema**

Of the 945 respondents 564 (59.7%) cited cancer or its treatment as the cause of their lymphoedema; 372 (39.4%) cited non cancer as the cause and a further 9 (0.9%) individuals were therapists or did not specify an answer.

![Bar chart showing causes of lymphoedema](image)

Questions 7, 8, and 9 relate specifically to those 564 members who signified that their lymphoedema was caused as a result of cancer or its treatment.
Question 7 – Preventative literature

Of the 564 respondents only 198 (35.1%) received any written preventative literature before, during or immediately after their treatment. 350 (62%) received none of the above and 9 (1.6%) individuals remember someone talking to them about it only.

Question 8 – Site of cancer

A total of 24 different cancers were noted by those answering this question, by far the largest number had experienced breast cancer with cancer of the cervix and melanoma as the second and third most cited cancers.

<table>
<thead>
<tr>
<th>Site of cancer</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breast</td>
<td>412</td>
<td>73.1%</td>
</tr>
<tr>
<td>Cervix</td>
<td>41</td>
<td>7.3%</td>
</tr>
<tr>
<td>Melanoma</td>
<td>24</td>
<td>4.3%</td>
</tr>
<tr>
<td>Uterine (womb)</td>
<td>21</td>
<td>3.8%</td>
</tr>
<tr>
<td>Prostate</td>
<td>11</td>
<td>2%</td>
</tr>
<tr>
<td>Genital</td>
<td>10</td>
<td>2%</td>
</tr>
<tr>
<td>Groin</td>
<td>2</td>
<td>1.8%</td>
</tr>
<tr>
<td>Non Hodgkin’s lymphoma</td>
<td>5</td>
<td>0.9%</td>
</tr>
<tr>
<td>Leg</td>
<td>4</td>
<td>0.7%</td>
</tr>
<tr>
<td>Ovarian</td>
<td>4</td>
<td>0.7%</td>
</tr>
<tr>
<td>Lymph glands</td>
<td>3</td>
<td>0.5%</td>
</tr>
<tr>
<td>Blood vessel</td>
<td>3</td>
<td>0.5%</td>
</tr>
<tr>
<td>Pelvic floor</td>
<td>2</td>
<td>0.4%</td>
</tr>
<tr>
<td>Bowel</td>
<td>2</td>
<td>0.4%</td>
</tr>
<tr>
<td>Axilla (arm pit)</td>
<td>2</td>
<td>0.4%</td>
</tr>
<tr>
<td>Bones</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Pelvis</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Bladder</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Throat</td>
<td>1</td>
<td>0.2%</td>
</tr>
<tr>
<td>Anus</td>
<td>1</td>
<td>0.2%</td>
</tr>
</tbody>
</table>
### Question 9 - Time lymphoedema occurred after cancer/treatment

The vast majority of the 564 members who put themselves in this category began to develop lymphoedema within two years. 401 (71.1%) of individuals developed lymphoedema within 2 years; 74 (13.1%) of people between 2-5 years; 40 (7.1%) between 6-10 years and 35 (6.2%) more than ten years after cancer/treatment.
Question 11 – Lymphoedema monitoring

Of the 945 respondents 767 (81%) members receive regular monitoring of their lymphoedema and 160 (16.9%) do not.

When considering this in relation to primary and secondary lymphoedema 486 (86.7%) of those with secondary lymphoedema are regularly monitored and only 281 (75.5%) of those with primary lymphoedema.
Question 12 – Place lymphoedema is monitored/treated

Of the 767 members regularly receiving treatment/monitoring six treatment centres were named. These classifications were specified by the members answers and it is not possible to say where the NHS clinics mentioned are based.

182 (23.7%) attended an NHS clinic; 354 (46.1%) attended a hospital; 195 (25.4%) attended a hospice for lymphoedema treatment; 65 (8.5%) went to private practitioners; 20 (2.6%) were cared for by their GP and 6 (0.8%) were cared for by community nurses.
There was some variance in treatment centres attended by primary and secondary patients as can be seen below.
Question 13 – How members heard about the LSN

From the 945 respondents a total of 17 means of hearing about the LSN were cited, these categories have been created from member answers and as such it is impossible to say where ‘leaflets’ were picked up.

<table>
<thead>
<tr>
<th>How heard about the LSN</th>
<th>Numbers</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>159</td>
<td>16.8%</td>
</tr>
<tr>
<td>Therapist/clinic</td>
<td>145</td>
<td>15.4%</td>
</tr>
<tr>
<td>Internet</td>
<td>111</td>
<td>11.8%</td>
</tr>
<tr>
<td>Hospice</td>
<td>109</td>
<td>11.5%</td>
</tr>
<tr>
<td>Word of Mouth</td>
<td>100</td>
<td>10.6%</td>
</tr>
<tr>
<td>Magazine article</td>
<td>74</td>
<td>7.8%</td>
</tr>
<tr>
<td>Leaflet</td>
<td>59</td>
<td>6.25%</td>
</tr>
<tr>
<td>Clinic</td>
<td>34</td>
<td>3.6%</td>
</tr>
<tr>
<td>No answer</td>
<td>29</td>
<td>3.1%</td>
</tr>
<tr>
<td>GP</td>
<td>29</td>
<td>3.1%</td>
</tr>
<tr>
<td>Breast care nurse</td>
<td>28</td>
<td>3%</td>
</tr>
<tr>
<td>Can’t remember</td>
<td>22</td>
<td>2.3%</td>
</tr>
<tr>
<td>Support group</td>
<td>17</td>
<td>1.8%</td>
</tr>
<tr>
<td>Radio/television</td>
<td>13</td>
<td>1.4%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>0.6%</td>
</tr>
<tr>
<td>Advert</td>
<td>3</td>
<td>0.3%</td>
</tr>
<tr>
<td>Public library</td>
<td>2</td>
<td>0.2%</td>
</tr>
<tr>
<td>District Nurse</td>
<td>2</td>
<td>0.2%</td>
</tr>
</tbody>
</table>
Question 14 – Membership of local support group

Of the 945 respondents 266 (28%) currently attend a local support group; 655 (69.3%) do not attend a local support group and 24 (2.54%) did not specify.

![Attend local lymphoedema support group chart]

Question 16 – Evaluate our service provision

In the following section members were asked to grade services already provided by the LSN – there is a high percentage of not specified for many of these, this is because not all members will have accessed all services.

Telephone help line

Of the 945 respondents 262 (27.7%) evaluated our help line as Excellent; 63 (6.67%) as good; 8 (0.9%) average; 5 (0.5%) unsatisfactory and 607 (64.2%) did not specify.

![Telephone help line PO 2006 chart]
Contact by letter/email

Of the 945 respondents 212 (22.4%) evaluated contact by letter/email as excellent; 76 (8%) good; 10 (1.1%) average; 6 (0.6%) unsatisfactory and 641 (67.8%) did not specify.

Fact Sheets

Of the 945 respondents 647 (68.5%) evaluated the fact sheets as excellent; 75 (7.5%) as good; 8 (0.9%) as average and 215 (22.8%) did not specify.
LSN Video

Of the 945 respondents 252 (26.7%) evaluated the LSN video as excellent; 124 (13.1%) as good; 9 (1%) as average; 4 (0.4%) as unsatisfactory and 556 (58.8%) did not specify.

LSN Website

Of the 945 respondents 214 (22.7%) evaluated the LSN website as excellent; 121 (12.8%) as good; 24 (2.5%) as average; 3 (0.3%) as unsatisfactory and 583 (61.7%) did not specify.
LymphLine

Of the 945 respondents 674 (71.3%) evaluated LymphLine as Excellent; 131 (13.9%) as good; 17 (1.8%) as average and 123 (13.02%) did not specify.

Question 17 – Rate LSN activities in importance

Eight areas of specific activity were identified and members were asked to rate each according to the importance of the activity to them, although an option of ‘not known’ was offered many members chose not to offer opinions on one or more specific areas of activity and these have been classified as not specified.

Working with the framework project

Of the 945 respondents 414 (43.8%) rated working with the lymphoedema framework project as very important; 143 (15.1%) as moderately important; 7 (0.7%) as low importance; 33 (3.5%) said they did not know how important this activity was and 348 (36.8%) did not specify.
Raising GP awareness

Of the 945 respondents 814 (86.1%) rated raising GP awareness as very important; 44 (4.7%) as moderately important; 12 (1.3%) as low importance; 6 (0.6%) said they did not know how important this activity was and 69 (7.3%) did not specify.

Lobbying government for better service provision

Of the 945 respondents 734 (77.7%) rated lobbying government for better service provision as very important; 75 (8%) as moderately important; 8 (0.9%) as low importance; 2 (0.2%) said they did not know how important this activity was and 126 (13.3%) did not specify.
Providing patient information

Of the 945 respondents 674 (71.3%) rated providing patient information as very important; 99 (10.5%) as moderately important; 5 (0.5%) as low importance and 167 (17.7%) did not specify.

Promoting local support groups

Of the 945 respondents 478 (50.6%) rated promoting local support groups as very important; 123 (13%) as moderately important; 49 (5.2%) as low importance; 20 (2.12%) said they did not know how important this activity was and 275 (29.1%) did not specify.
**Using the media to raise awareness of lymphoedema**

Of the 945 respondents 570 (60.3%) rated promoting using the media to raise awareness of lymphoedema as very important; 157 (16.6%) as moderately important; 21 (2.2%) as low importance; 10 (1%) said they did not know how important this activity was and 187 (19.8%) did not specify.

**Lobbying the NHS for better service provision**

Of the 945 respondents 747 (79%) rated Lobbying the NHS for better service provision to raise awareness of lymphoedema as very important; 50 (5.3%) as moderately important; 11 (1.2%) as low importance; 6 (1.2%) said they did not know how important this activity was and 131 (13.9%) did not specify.
Supporting individual members

Of the 945 respondents 573 (60.6%) rated Supporting individual members as very important; 149 (15.8%) as moderately important; 21 (2.3%) as low importance; 16 (1.7%) said they did not know how important this activity was and 186 (19.7%) did not specify.

Drawing data from the above it is possible to ‘rank’ which of the LSN activities the members consider to be most important to them. It should, however, be noted that each person rates importance to themselves based on a multiple of variable influences and their knowledge of the activity, as such whilst it is interesting and should to some extent influence the forward planning of the organisation any decisions should take into account the whole local, national and international picture and the financial, organisational and time restraints of the Lymphoedema Support Network.

Based on the above data the membership ‘rates’ our activities in order of importance to them as

Raising GP awareness
Lobbying NHS to provide better services
Lobbying Government for better service provision
Providing patient information
Using the media to raise awareness of lymphoedema
Supporting individual members
Working with the framework project
Supporting local support groups.
Conclusions from quantitative data

The quantitative data gathered and reported above paint a very positive picture of the LSN, as an organisation that is meeting the needs of its members and providing high quality services and information. With the exception of working with the framework project the activities identified as of highest importance to the membership are ones which feature both in our general plans and within the BLF project.

The framework project and the achievements it has and will go on to make are probably poorly understood by the membership despite various articles in lymphline.

The low rating of supporting local support groups is probably due to the low number of respondents who are members of local groups and appreciate their valuable place within the network of support.

Action to date

The data from all returned questionnaires has been entered and the quantitative data analysed and reported above. Any members who expressed a wish to offer support of any description will be followed up as below.
<table>
<thead>
<tr>
<th>Offer of help</th>
<th>Number of members</th>
<th>Follow up action</th>
</tr>
</thead>
</table>
| Attend office to help with mail out   | 27                | • Create database of members interested in volunteering for mail outs.  
• Write to each thanking for offer.  
• Give list to Jenny |
| Make a donation to the LSN            | 252               | • Create database of all members interested in making a donation.  
• Cross reference database with known donors  
• Review opportunities/ways of donating to the LSN  
• Send out ‘how to make a donation’ information to all on database.  
• Review response. |
| Use story to raise awareness          | 187               | • Make a database of members interested in allowing their story to be used.  
• Review membership files – send thank you/ can we keep you on file letter to those not considered to be appropriate at the present time.  
• Send out pre designed form asking for main features of story and create an e file.  
• Carry out telephone interviews with a cross section of membership volunteers and create e file. |
| Hold a fundraising event for the LSN  | 31                | • Send out fundraising packs. |

Follow up action

As far as has been possible (some members declined to give contact details) all members who categorised any aspect of our services as unsatisfactory have been contacted directly by me and their dissatisfaction addressed – The majority of these were around unanswered emails/letters and no changes to any LSN protocols are suggested.

Any direct request made on forms for fact sheets/information etc has been dealt with.

The qualitative data from all returned questionnaires has been entered and will now undergo a thematic analysis where by all comments are grouped by themes to allow the large amount of raw data to be reduced to workable amounts. This will be carried as a separate exercise by myself and Trustee Ros Lam to prevent bias. Once both analyses are complete they will be considered along side each other with another member of the trustee board and a consensus thematic analysis produced.
Appendix IX

Submission from Target Ovarian Cancer: ovarian cancer survivorship model
Clinical
- First surgery by specialist cancer surgeon gynaecological oncologist rather than gynaecologist
- Access to Specialist Nurse Gynaecological CNS: many are sole practitioners which means women may only see them once at the point of diagnosis. Women who have more regular access to a gynaec CNS experience a greater sense of support during treatment 1
- Access to clinical trials, 61% of women were not offered the chance to participate in a clinical trial
- Access to a treatment centre that runs clinical trials 3
- Acquired resistance to chemotherapy treatment on relapse
- Narrow treatment options in relapse due to lack of chemotherapy drugs currently appropriate as second or third line treatments
- Under referral to psychological/psycho-sexual services impacts on relationships. Depression and anxiety – common in ovarian cancer survivors 3
- Intensive nature of treatment for ovarian cancer 4

<table>
<thead>
<tr>
<th>Individual</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to emotional support as preferred by the individual to formal psychological treatment such as counselling, GP, CNS or support Group 1</td>
<td>Isolation after intensive treatment leaves survivors’ feeling abandoned and low in moo</td>
</tr>
<tr>
<td>Access to a range of complementary therapies</td>
<td>Institutional pessimism of survivorship prospects for women diagnosed at later stages of the disease</td>
</tr>
<tr>
<td>Access to other services to improve quality of life e.g. lymphodema services</td>
<td>Traditionally pessimistic literature commonly available on the web with bleak statistics and inference on women’s state of mind</td>
</tr>
<tr>
<td>Access is often hampered by under referral by MDT members due to a variety of practical (infrequency of contact), institutional and idiosyncratic local practice 1</td>
<td>Gynaec CNS’s often thinly spread due to lack of NHS investment leading to lack of support groups or lack of publicity of existing support groups again compounding a sense of abandonment</td>
</tr>
<tr>
<td>Fear of relapse</td>
<td></td>
</tr>
</tbody>
</table>

Citations
1. Target Ovarian Cancer Pathfinder Study, Synovate Summary Report, June 2009
5. Ovarian cancer action National Awareness Survey 2006/07, Dr Foster
Appendix X

Submission from a consortium of brain tumour organisations: Meningioma UK, Samantha Dickson Brain Tumour Trust and the International Brain Tumour Alliance

The caregiver’s survivorship challenges
Introduction

The fatigue, distress, depression, grief and challenges of day-to-day living which are often faced by a patient diagnosed with a primary malignant brain tumour can also be experienced by that patient’s caregiver. Therefore, cancer survivorship becomes not a one-person journey through the maze of medical, social and economic aspects of the disease but a journey which includes caregivers (and members of the brain tumour patient’s family) as well.

Brain tumours – of which there are over 120 different types – combine the worst of the neurological diseases with the worst of cancer. Depending on the type and grade and in which part of the brain it is located, a brain tumour can affect cognition, physical abilities, personality and emotion. Brain tumours afflict people of any age - from tiny babies to the elderly - with equal ferocity, regardless of background, race or geographic location. Brain tumours can rob people of their sight, their mobility, their hearing, their taste, their smell, their speech, their memories, their jobs, their dignity, their relationships, their driving license (because many brain tumour patients also suffer seizures) and their personalities.

Brain tumours “not only confer high risk of death and severe disability, but also threaten to steal what is held so highly as the essence of human life: the mind and the spirit.” ¹

Brain tumours strike at the very core of who a person is.

The causes of brain tumours are largely unknown so there are no prevention programmes for them nor any realistic screening programmes. There is no known preventative option by healthy living, diet or exercise.
Every year, 200,000 people worldwide develop a primary malignant brain tumour. Countless others, such as caregivers and family members, are also devastated by the effects of the brain tumour on their loved ones and themselves.

All of the deficits mentioned above, capture the uniqueness of surviving and living with a brain tumour, both for the patient and the caregiver.

While the primary focus of medical attention and associated support mechanisms must of course remain on the brain tumour patient, it is also imperative that any cancer survivorship initiative must also take into account the caregiver’s needs and support pathway as well.

THE CAREGIVER’S SURVIVORSHIP CHALLENGES

In an article on “Caregivers of persons with a brain tumor: a conceptual model”, Paula Sherwood et al state: “The caregiver of a person with a PMBT [primary malignant brain tumour] often faces cancer-related issues such as fatigue, depression and grief, related to a potentially short, terminal trajectory of disease. However, owing to the location of the malignancy, the caregiver of a person with a PMBT may also be forced to deal with neurological sequelae, such as alterations in functional status, cognitive status, and the presence of neuropsychiatric symptoms.”

In addition, the authors of the same article state: “Coping with the oncological and neurological sequelae of a PMBT, then, requires both the functional ability to perform physical tasks on behalf of the care recipient, as well as the emotional health to contend with the potential decline and loss of the care recipient, and the neurological sequelae that are associated with such a decline.”

Recent studies indicate that only 18% of patients with primary brain tumours are able to return to work as a consequence of their disease and ongoing treatment. This further impacts on the economic fragility of the situation, adding additional stress to the caregiver who may also have to give up his or her job to care for a brain tumour patient.

SOME SOLUTIONS

We would very much like to see the additional needs of caregivers factored in to the National Cancer Survivorship Initiative through a programme of support and information.

Such a structure could include:

- A “systems navigator” who can help steer patient, caregiver and family through the maze of post-operative care, providing guidance on securing benefits where appropriate, providing information on the practical aspects of day-to-day living (both for the patient and the caregiver) and also signposting
to organisations and agencies who might be able to assist or answer questions related to the cancer survivorship journey.

- **More studies and counselling for “anticipatory grief”**. This is a concept that, unfortunately, has received very little in the way or attention or study. Anticipatory grief is a process in which you can experience all the same stages of grief – disbelief, anger, depression, sadness, emotional fragility and constant crying, guilt and then acceptance – even before the actual passing of a loved one. It is a reaction to the shock of a cancer diagnosis and perhaps can be described as representing a “mourning period” where both patient and caregiver realise that the life they knew is gone (along with the control they may have had in their lives) and they will have to adjust to the “new normal”. But, just as with grief at the real death of a person, there are coping mechanisms and support systems that can be provided to caregivers should they experience this devastating reaction.

- **More education about critical skills for caregivers**. This could include practical skills such as how to lift a patient properly without doing damage to the patient or caregiver; how caregivers can communicate better with doctors; how caregivers can be better supported if they are suffering from depression; tips for caregivers about maintaining their own health; readily available respite care information; support groups for caregivers; etc.

- **More education for doctors on how to deliver bad news**. Frequently both the patient and the caregiver-to-be are given the news of a cancer diagnosis together at the same time. Many patients and caregivers have told us they can remember every word said by the doctor when the diagnosis was delivered. We have had reports of totally inappropriate “bad news breaking” by doctors when words spoken during that first delivery of the diagnosis have literally scarred the attitudes of both patient and caregiver towards survivorship and living with cancer.

- **The development of a “cancer caregivers survivorship model”**. Caregivers are survivors of a cancer diagnosis too.

### A FINAL WORD FROM CAREGIVERS OF BRAIN TUMOUR PATIENTS

We asked some of our contacts who care for or who have previously cared for a person with a primary malignant brain tumour to send us some of their thoughts on what it feels like to be a caregiver. We also quote anonymously from an online support group for brain tumour patients, caregivers and families. The responses of the caregivers about their own survivorship on the cancer journey are heart-rending and disturbing as they describe their own experiences and cry out for help and support.

- A woman whose sister has a malignant brain tumour wrote: “There is a constant knot in my stomach and a huge build-up of stress from MRI to MRI.”
Caring for someone with a brain tumour feels like you can never take a deep breath. That is how I felt for the first year or so from diagnosis.”

She added that she was “paralysed with sadness” and “experiencing a constant roller coaster of emotions”.

❖ A man who cares for his wife who has a malignant brain tumour wrote: “Words which describe my own survivorship of my wife’s cancer diagnosis include: anger, depression, helplessness, frustration and uncertainty. Her inability to drive is a major factor and puts an extra burden on me. There are financial pressures and there has been a change in our social situation – some people avoid us and we sometimes feel stigmatised.”

❖ Another woman describes a close friend with a brain tumour to whom she is a caregiver: “It can be hard to put someone else first all the time – to let someone go but be there for them still. It’s like standing on the shore watching [him] out at sea. Sometimes the waves bring him back closer to me and sometimes the tide takes him away again.”

❖ The mother and caregiver of a brain tumour patient wrote: “For the first 18 months after my son’s diagnosis, I barely survived, neglecting my own health and mental well-being and experiencing periods of intense depression and despair. I now know I was suffering from anticipatory grief. But at the time, I felt I was going mad with the shock and demands of caring for someone with such a serious illness (with all its devastating consequences) when I had never had experience of that kind of situation before. Looking back, I think that had I been better supported as a caregiver, the first year and a half of our cancer journey could have been much more tolerable. I could also have provided a much higher level of support and care had I, as the caregiver, been able to access more information in a timely manner and understand what my own survivorship needs were, as well as my son’s.”

❖ A young woman said: “As caregivers we sometimes feel that we are on a treadmill and that we have no choice but to keep pounding away.”

❖ A wife explained her caregiver’s journey: “I too felt terribly cheated and resentful about how my husband’s 5 year illness affected my life. I did not have to give up a job, but I did have to turn down many opportunities to travel and take on special projects and things that I would have loved and that would have advanced my career. We have a teenage daughter who has had to live under the shadow of this terrible disease for five years. The last few months of [my husband’s] life were a living hell for me (as well as for him, of course), in which I was exhausted all the time and couldn't really get out even to see a movie or something. The last three weeks were unbearable, with medication and turning him every few hours round the clock, and money flowing out much faster than it flowed in. He just passed away this Monday, and I am filled with this swirl of grief, exhaustion, relief, even moments of excitement, thinking about having a new chance at life. I will miss him terribly, but it was so awful for so long.”
A 32-year old caregiver to a brain tumour patient wrote: “Is there an end to sacrificing? We have had this brain tumor journey since 2001. Today I find...that I have sacrificed all my dreams, my life and everything and I am at a total loss... I had started my MBA degree program and had to let that go because I had to take care of my husband. I had to visit my mother who was undergoing a breast cancer surgery, wasn't able to do that because of my husband's health. I had to kill my dream of going on any vacation due to his health. Had to kill my dreams of raising a family. Had to let go of my youth and my precious time without expecting anything from a partner. Had to sell our home for this stupid BT...Is there an end to this?”

This is from a man who was caregiver to his wife on a glioblastoma brain tumour journey: “Do not neglect your own physical health. As my wife’s illness progressed, she found it difficult to multitask and I became the chief cook and bottle washer in the home. I admit that what we ate was what was convenient to buy and to cook. If it looked good on the frozen food package then that would be our meal. Naturally, ice cream, chocolate, cakes and pastries always look good and convenient and how could we deny ourselves some ‘comfort food’? I later paid the price with the emergence of type II diabetes, brought about, so my doctor said, by poor diet while being a carer, lack of exercise and stress.”

And finally, in an effort to help and support another brain tumour caregiver, a woman (whose husband was taken into hospice), gives some words of advice:

“My health was in jeopardy (heart problems)... It was the stress of taking care of a brain tumor patient for all those years that was causing tachycardia... I am just saying: take care of yourself first so that you can then take care of others! My husband was given 3 years to live. He is here 24 years later which is wonderful. But don't live like they are going to die. Live like they are going to live. That was my mistake for many years.”

It is clear from these quotes, this anecdotal “grey literature”, that the role of caregiver reflects in many ways the cancer survivorship journey of the patient.

**We would strongly urge any survivorship initiative to address the challenges not only faced by the cancer patient but the caregiver as well.**

“Surviving as a caregiver to a brain tumour patient brings many profound challenges,” said one woman. “To be the very best caregiver I can be to someone who I love so deeply means that I have to have the resources and strength to carry on no matter what. This is a journey that none of us, in our worst nightmares, ever expected to take. Surviving it needs a huge amount of support and care – for both the patient and the caregiver.”

★★★★★
Submitted to Cancer 52 on Monday, 22 June, 2009 for the C52 - National Cancer Survivorship Initiative (NCSI) Report

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Notes:


2. Estimates supplied by the Central Brain Tumor Registry of the United States based on GLOBOCAN 2002

3. Sherwood, Paula; Given, Barbara; Given, Charles; Schiffman, Rachel; Murman, Daniel; Lovely, Mary, Caregivers of persons with a brain tumour: a conceptual model, Nursing Inquiry 2004, 11(1): 43-53

4. Ibid

5. Kalili, op cit, page 5