

Clinical Nurse Specialists working with people with **rare and less common cancers**

Some personal perspectives from nurses and patients



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This report

As part of Cancer52's commitment to improving quality of life for people with rare and less common cancers, this report aims to showcase the work of the Clinical Nurse Specialist and the invaluable support and humanity they bring to treatment and care.

We believe that this is best demonstrated through the words of nurses and patients themselves as they tell their unique and sometimes extraordinary stories.

Within this report, we bring you some personal perspectives, from both nurses and patients, alongside supporting information about the importance of the role of the CNS.

Our thanks to all those who contributed and to those whose support made these interviews and report possible.

Jane Lyons
CEO of Cancer52



Introduction

Being diagnosed with cancer is the first step on a challenging and often highly stressful journey. Yet, for people diagnosed with a rare or less common cancer, life is arguably a little harder.

People with a rare or less common cancer are disadvantaged all the way through their journey with cancer. From the speed of diagnosis through to treatment and research, people with rare and less common cancers often get a second-class service and a poor deal.

However, there is one clear factor that provides patients with a significant advantage and a more positive experience; access to a Clinical Nurse Specialist (CNS). This one thing improves a patient's experience in every other area.

The analysis of the data also showed clearly that no matter what the cancer type, if people are supported by a clinical nurse specialist they feel more positive about the care and the treatment they receive.

The significance of the role of the CNS was highlighted in the Cancer Strategy of 2015 with Recommendation 61 encouraging providers to ensure that all patients have access to a CNS or other key worker from diagnosis onwards. This report tells some of the personal stories behind the recommendations and the data.

Experience of care

In 2015 Cancer52 commissioned an analysis of the results from the National Cancer Patient Experience Survey, focused on the experiences of people with rare and less common cancer.

The aim was to understand more about where care and cancer services differ between those with the big four cancers and everyone else, as well as understanding more about the impact that has on people with cancer and their families and friends.

What the results clearly demonstrated, was that people with a rare or less common cancer have a poorer experience in almost every aspect of their treatment and care.

The role of the Clinical Nurse Specialist



Cancer52's analysis of the data from the National Cancer Patient Experience Survey shows that access to a Clinical Nurse Specialist (CNS) improves patient experience of cancer care. Why? I believe

that is because CNSs are highly experienced, well qualified and uniquely placed to support patients with rare and less common cancers; by offering holistic, expert care which crosses care boundaries and which supports people emotionally and practically as well as physically.

Being diagnosed with cancer is deeply upsetting and confusing for patients and their families and friends. It can be difficult to make sense of everything, to have to make big decisions about treatment and to navigate through an increasingly complex health service to find the right care. This is an even greater challenge if you have a rare or less common cancer.

Cancer CNSs support patients through diagnosis and treatment by providing psychological support, they help with decision making and they also help people to stay well and out of hospital. They provide invaluable information too, which helps people to understand what is happening to them and empowers them to manage their own care. Communication with and between services is another important aspect of their role, joining up hospital,

community, hospice and other care, thereby helping patients to have seamless and continuous care. In essence, being a CNS is about being in a position of trust and respect, and being someone that patients and their families can rely on in a time of acute distress.

There are more than 3000 oncology (cancer) nurse specialists in the UK,¹ many of whom care for patients with specific tumour types. More than half of all CNSs care for people with a rare or less common cancer, including some specific tumour groups such as sarcoma, gynaecological cancers and mesothelioma.² However, there is some variation across geographical areas, which means that not everyone with a rare or less common cancer will have access to a CNS. Though the number of CNSs is increasing steadily year on year,³ so is the number of people with cancer. Therefore, there are still some patients who miss out on the opportunity to make use of such an invaluable resource. Sadly, it is those people with a rare or less common cancer who are most affected.

There is no doubt that the NHS is currently under severe pressure. However, the evidence shows clearly how valuable CNSs are, not just for patients and their families, but for health services too - they are cost effective, efficient and lead to better health outcomes for people with cancer.⁴ They are a vital part of high quality care for people with rare and less common cancers and my hope is that in the future everyone will have access to their skills, compassion and expertise.

Catherine Oakley, chemotherapy nurse consultant, Guys and St Thomas' Foundation Trust, and former president, UK Oncology Nursing Society

Personal perspectives from nurses and patients

Michelle Judge and Gillian Bowkett



Michelle Judge is Cancer of unknown primary and rare cancer Clinical Nurse Specialist at Worcester Acute Hospitals NHS Trust. Here she talks about her experience of being a CNS.

When Michelle sees her patients, she brings with her a wealth of experience and expertise. Her nursing career spans three decades, and in that time, she has cared for and supported thousands of patients and their families, often in times of distress as well as in hope. Much of her working life has been spent taking care of people at the end of their lives. "I developed an interest in palliative care in the 1990s, when patients really weren't getting very good care. Things have moved on hugely since then. Working in palliative care gave me more time to spend with patients and a chance to enhance their quality of care," she says.

Michelle's current role is as a Clinical Nurse Specialist for patients who have a rare cancer or a cancer of unknown primary. Rare cancers can be challenging to investigate as often there are no specific pathways to follow. Michelle explains, "Patients often need special investigations and treatment, which they can't always have locally. Some people end up having to travel hundreds of miles to have a test. One lady recently had to travel to Liverpool for a scan."

And it's not just the treatment that is difficult if you have this kind of cancer. "People with rare cancer have a particular need for psychological support, because of the uncertainty of their diagnosis. They don't know how successful treatment is likely to be, or how long they will live. Some people are young too, with families and jobs and that's hard to come to terms with and plan for."

Michelle thinks being a Clinical Nurse Specialist gives her a unique opportunity to provide individual support to patients and their families. "Everyone with cancer needs a named contact, because everyone needs to be treated as an individual. It's that constant presence. Patients might move from one team to another, but you're always there as that main point of contact." She is also a great advocate for her patients and tenacious with it. "I help patients to plan. They know that they can pick up the phone and ask any questions they have. I co-ordinate their care, make referrals, and do all the things that they shouldn't need to have to battle for. Whenever I can, I try to cut through the red tape and make sure they move forwards."

Worcestershire's cancer of unknown primary and rare cancer service is relatively new, and an unusual one for a small NHS organisation to have. It was set up because of recommendations made by the National Institute for Health and Care Excellence, which said that every hospital with a cancer service should provide one. Michelle is justifiably proud of the service she set up from scratch just two and a half years ago. "Because treatments are improving, my case load is growing and I'm very proud of what the service provides; it's making an impact. I know that whatever I do next it will carry on. People with this kind of cancer have never had a service like this before and it makes a real difference," she says.

Thinking about the future of the service, and what else would make a difference to her patients, Michelle can think of a number of issues that need to be tackled. These include patients being able to access more specialised services locally, a better understanding of rare cancers by GPs and quicker diagnosis. She says, "GPs sometimes don't know much about rare cancer and people can have symptoms for five years or more before they are diagnosed. If they don't have a specialist nurse or service they get bounced around all over the place from person to person, and their investigations are prolonged. Some people are very sick by the time they reach us."

As well as supporting her patients as they navigate their way through treatment and beyond, Michelle also acts as a source of knowledge in an uncertain world. Lack of information is one of the most challenging aspects of living with a rarer type of cancer, she explains, "Patients need specialist information and they often don't get it if they don't see the right specialists. I can get and give the right information. Quite often they go and see the consultant and then afterwards they have no idea what's happening to them. It can be really frustrating, but I can give them that reassurance of knowing what to expect next."

It's also clear that Michelle has great warmth and admiration for her patients and is particularly proud of one of her younger patients. "I only have a few younger people at the moment, but one of them is amazing. She is really getting on with life; throwing herself into things. She works, she's a mum and she fundraises. I ask myself how I would be if I was in her situation. She looks well too, which is part of the challenge; people think she isn't ill and she had to reassure her colleagues that she wasn't skiving!"



Gillian Bowkett is one of Michelle's patients, and here she talks about life with cancer and the important role that Michelle plays in supporting her and her family.

Gillian's friends have described her as inspirational, and it's easy to see why when you listen to her talk about her life with cancer. Just before Christmas in 2014, Gill was diagnosed with a neuroendocrine tumour in her pancreas, which had spread into her liver as well. It's a rare type of cancer which grows slowly and is difficult to diagnose.

As Gill explains, "I first had symptoms in 2010. I was having diarrhoea every day and losing lots of weight. My GP thought it was irritable bowel syndrome (IBS) and that's what I treated it as for three years, eliminating various food groups to

no avail. The day they told me it was cancer was a real shock, I thought it could be gallstones as that was why a GP requested an ultrasound, but I wasn't prepared for cancer."

Gill has regular hormone treatment to slow down the growth of the tumours, but at the moment it is the best treatment available. "I can't be cured – if it had been caught before it got into my liver, then maybe I would have had a chance of surgery, but there are lots of tumours in my liver so that's not possible. I try not to get cross about it as it would eat me up if I did - you can't know everything that's going on inside your body. It's bad luck, but I'm trying to stay positive."

The hormone treatment is a regular injection every 28 days, and Gill feels lucky that, on the whole, she has few symptoms. In fact, as she explains, sometimes having cancer and feeling so well most of the time, is a bit surreal. "I have my treatment in the place where everyone has chemotherapy. I could have it at home, but sometimes I forget that I have it, because I feel and look OK. So, I go in for treatment to make it feel more real. I feel guilty sometimes as people say how well I look, but it's all happening on the inside. I feel like a fraud!"

Dealing with an uncertain future is par for the course when living with cancer and the emotional and mental toll can be high. Gill's Clinical Nurse Specialist, Michelle, suggested she see a psychologist to talk about how she feels, and at first she was sceptical. "They are treating me and waiting to see what will happen, but I know that eventually they will run out of options. Michelle suggested seeing a clinical psychologist at the hospice and I said, 'I'm not going there; people die there'. But Michelle brought me round by saying that I needed to see someone who understood what I was going through. And so, I went, and it's brilliant because I can say whatever I want."

When asked what the most challenging part of living with cancer is, Gill says, "Not knowing how much time I have left. No two people have the same journey with this and many people have had it for 10-12 years when it's diagnosed. It grows slowly. I almost feel lucky that they can manage it. I look well, it's not impacting too much, it could be worse. It's the emotional load of it that's hard." The feeling of tiredness can be overwhelming but Gill now works part-time, as a teaching assistant, at a primary school so she can rest in the afternoons before her boys return from school.

Because she has a rare type of cancer, Gill says that her consultant and Clinical Nurse Specialist are on the learning journey with her, supporting her practically as well as emotionally. It's clear that the relationship with her Clinical Nurse Specialist, Michelle, is particularly important. "I see Michelle every 4 weeks and if I have any problems she is there at the end of an email or a text. I can call her for a chat if I feel low. It's a good relationship, she stays in touch and she comes to my appointments with me. I can ask her anything, sometimes it's just the little things that you need to know or that are important. She has that specialist knowledge but she's learning all the time too. She's very calming and we have a giggle. I would feel less reassured if she wasn't there," she says.

Gill is very passionate about raising money and awareness for the Neuroendocrine cancer charity, the NET Patient Foundation. "I've done a sponsored walk, bake-off teas, a Christmas bazaar and I'm making zebras and owls to sell at the moment. I like to keep myself busy, have a laugh and just get on with life. Crying is just a waste of my emotional time. I do cry, but sometimes I think what's the point?" she says. The Zebra is the worldwide symbol for the awareness of NET Cancer.

As well as raising money for the NET Patient Foundation, Gill does as much awareness raising as she can, because, as she says, the symptoms

can be easy to misdiagnose. "This type of cancer often looks like irritable bowel syndrome, and there are so many people with that now, I worry that there are going to be loads of undiagnosed neuroendocrine tumours. I do quite a lot of awareness raising about symptoms; I helped at a stand at the hospital for World NET Cancer Day, 10th November, and delivered information to local GP surgeries. I have even suggested to friends with similar symptoms that they should go and see their GP to eliminate it."

Living with cancer is tough for everyone, but Gill has lots of support from family and friends, and she says it has changed her in ways she didn't expect. "I used to be a bit of a control freak; I would always take over and organise everyone. Now, I just go with the flow. So, before the cancer I would have been packed to go on holiday about two weeks before we went. Now I pack the night before and just throw a few things in a bag. Some things don't matter as much now, I'm much more chilled and I realise what's important. If I do have pain I take painkillers and rest, listening to my body and not carrying on regardless. I make more of an effort to see people too, and I appreciate things more. I've grown as a person since having cancer. I have cancer but I'm still me, I'm carrying on. It's not all doom and gloom, I'm taking control and I'm still having a laugh!"

Tracie Miles



Tracie Miles is Eve Appeal Information Nurse and Gynaecological Nurse Specialist, United Hospitals Bath.

Tracie has been nursing for more than three decades and in that time, she has gained a wealth of experience and expertise.

She currently has two roles; one as Information Nurse at The Eve Appeal, the UK's Gynaecological Cancer Research Charity, and the other as Gynaecological Nurse Specialist based at Royal United Hospitals in Bath. The roles are very different. In one, Tracie is providing face to face nursing support to women throughout their journey with cancer, and in the other Tracie is giving telephone and email support around symptom awareness and the whole cancer journey. She also takes part in symptom awareness campaigns and teaches others about gynaecological cancer.

Tracie's role at United Hospitals is close to her heart, "I started in this role 15 years ago, and it's gone from strength to strength. I was coming to it almost new to gynaecology, so I read everything I could, including the Calman Hine cancer report which describes the whole cancer journey. I decided that's how the care should be given, so that women are supported all the way through. It's quite an unusual way of doing things and an unusual role for a nurse specialist."

It's a varied and busy role. Tracie is involved in a number of different clinics, including a pre-op assessment clinic. Tracie explains what this is and the important role it plays in a woman's recovery. "We see women here who know they have cancer. They have blood tests and investigations and see the anaesthetist. We also do their consent form. It means the woman is more in control and more able to ask questions. She is in her own clothes, not in a theatre gown waiting to have her operation. It makes such a difference to patients because it's like practicing to be a patient. Women need all the information about the impact of treatment, so that they're prepared and have realistic expectations. Their recovery is so much better if they have this kind of fully informed consent."

Tracie runs a BRCA counselling and consenting genetics clinic too. "The BRCA 1 and 2 genes are the ones that carry a risk of developing ovarian and breast cancer; it's the one Angelina Jolie has," she says. "Women who have had a high grade ovarian cancer may have a BRCA test, as it has implications for them and for their families. If they carry it, then their children and their siblings have a fifty percent chance of carrying the gene too."

It's clear from talking to her that Tracie is passionate about the work she does. When asked what it is that she loves about her role, she says, "The nurse navigator aspect of it. That's what's great, holding a woman's hand and that of her family's and walking with them through the whole journey. It's a crazy jigsaw of care and services and I make sense of it for them, fitting services together." Tracie explains further, "I could be working out how to get an investigation or a scan quickly, or how to get benefits advice, or giving support around body image. It's a holistic service. Women need to know the whole picture and they need someone who understands the science, and who can put that into words they can understand."

As well as her navigator role, Tracie provides lots of emotional and psychosexual support. She is acutely aware of the impact of a cancer diagnosis and its treatment, and the sometimes long term consequences of that. "That's one of the most difficult things for patients. There are all sorts of side-effects and some can be life changing. Women may lose their hair, they may have diarrhoea, constipation or cystitis, they don't look or feel like themselves anymore and their sex life is affected. Women sometimes stop feeling like women; some of the treatment affects their body image. Some of the surgery can be disfiguring and can lead to early menopause. It can affect a woman's sex life and relationships and it can take a long time to feel in control again," she says.

As information nurse at The Eve Appeal, Tracie provides support around all the aspects she encounters in her clinical role. "I answer phone calls and emails about anything to do with gynaecological cancer, but most often it's about symptom awareness. So, a woman might call and say 'I've got bleeding after I have sex, should I see my GP?' I give them the confidence to go and see their doctor, I signpost them to other information about cancer and support groups." She goes on to say, "I've learned loads at The Eve Appeal about raising awareness of symptoms; it's a massive task. It's hard to get your voice heard among the big four cancers, but those with a less common cancer make up more than half of people who have cancer overall. Surely, we should give the other cancers more of our support?"

Ingela Oberg



Ingela Oberg is Clinical Specialist Nurse in Neuro-oncology at Addenbrooke's Hospital, Cambridge University Hospitals NHS Foundation Trust.

Ingela's job title of Clinical Specialist Nurse tells you something about her role; but by no means everything. Her main role is supporting patients with brain tumours and their families, but Ingela also teaches, advises other health professionals and influences on a national level to improve patient care. She has even been a medical advisor to Hollywood!

But her patients and their care always come first, and Ingela has a very personal reason for choosing to specialize in this area.

"Neurosurgery is close to my heart. I had a younger brother who died of a brain tumour and I think that makes it easier for me to understand how people are feeling, and what they're going through." She goes on to explain what keeps her going, in what can be a stressful and upsetting role. "My Mum said that if she had had access to someone like me 25 years ago, when my brother was diagnosed, it would have made such a difference. They wouldn't have felt so alone. I'm there to make the journey as smooth as possible and to give people the help my mum didn't have. I just remember that I

didn't give them the cancer, but I can help them get through it."

Ingela supports and cares for people with all types of brain tumour, both cancerous and non-cancerous. Non-cancerous tumours can be cured, malignant ones can't, but they can be treated. Some grow very slowly, others are more aggressive which means the future can be unpredictable and uncertain. This means that some families are facing just a few months or years left together, a situation which Ingela finds upsetting. "The hardest ones are people that are my own age, with a family when you know that they won't see their children grow up and then sometimes I'm choking back tears when I talk to them," she says.

Because of where the tumours are, they come with a highly individual set of symptoms. They can also have an impact on any aspect of life, as Ingela explains. "When people have a brain tumour they worry that it's going to affect their personality and who they are; that the tumour will turn them into a different person. They lose any privacy and dignity. They can't lock the bathroom or toilet door in case they have a seizure. They often can't drive either and that has a big impact on their independence."

Treatment for brain tumours varies depending on the type of tumour and how quickly it's growing. Some patients have surveillance which could mean having surgery or medicines and then having a brain scan every six months to see whether the tumour has grown. Addenbrooke's is at the cutting edge of new treatments for brain tumours as Ingela explains. "With malignant tumours the surgeon can only remove what they can see with the naked eye. Addenbrooke's is one of the few places that uses a new treatment called 5-ALA. It's a drink that's given to patients before surgery that makes their tumour glow pink so it can be seen really clearly and more of it can be removed. It then makes chemotherapy and radiotherapy more effective.

It's costly though which is why it's given in specialist centres and it's really been the biggest leap forward in treatment for brain tumours."

Depending on where their tumour is, some patients also have 'awake surgery'. "We use the technique when a tumour is close to the part of the brain that deals with speech or movement," Ingela says. "The patient starts off asleep, as you would usually, so that they can be positioned and the surgery started. Then, at the point where the surgeon is ready to remove the tumour, they're woken up enough so that they're still sedated, but they can talk. One of my colleagues sits with them and holds their hand and talks to them and they're very calm. Some people don't remember it at all, whereas others remember all of it. You would think they would find it scary, but they don't!"

The role of the Clinical Nurse Specialist is a unique one, and it provides patients with a point of contact, an advocate, a clinical expert and in many ways, a friend. As Ingela says, "A good Clinical Nurse Specialist is someone who is kind, patient and honest as well as knowledgeable. You can't bluff your way through this, you have to know what you're talking about. Breaking bad news is one of the toughest things to do – you can give patients that touchy feely side that perhaps the consultants don't have time to do. So, you can hold their hand, give someone a hug, ask them how their children are coping and talk things through."

Ingela has been a nurse for almost 20 years and has seen hundreds of patients come and go. But some always stick in her mind. "I remember one patient who was diagnosed with a malignant tumour and he was given maybe about 18 months to live, but only if he decided to have treatment to prolong his life. He was married with a teenage daughter and his wife was disabled. The insurance policy for his mortgage would only pay out for his type of brain tumour if he had less than a year to live. So, he declined

all treatment so that his wife and daughter would be financially cared for and would have their house when he was gone. When he told me what he was going to do, all I could do was hug him and tell him how incredibly brave and selfless I thought he was."

Lynne McCallum and Matt Schofield



Lynne McCallum is Clinical Nurse Specialist for HPB cancers and neuroendocrine tumours and The Christie NHS Foundation Trust.

Lynne has been a cancer nurse since she qualified and it's always been what she wanted to do. But it's taken her down a road that many people would see as challenging; looking after patients at the end of their life. "I look after people with hepatobiliary cancer, which is cancer of the pancreas, liver, bile ducts and gall bladder. Because of the type of cancer this is, we are often talking about end of life care. The prognosis is often poor, and people sometimes have a year or less to live after diagnosis. People say to me, 'Doesn't that make you sad?' But it doesn't, not really as I know that I am doing something to help them. I can give them the skills that they need, to live as well as they can with their cancer diagnosis," she explains.

As a Clinical Nurse Specialist, Lynne is clear about her role and the benefits she brings to her patients. She says, "As a specialist nurse, you need to be a good listener and communicator. You need to be patient, and an advocate for them, so you always have their wellbeing in mind. Sometimes you need to challenge decisions too."

Lynne goes on to say how important it is for patients with a rarer type of cancer to have access to her knowledge and expertise. "People with a rarer kind of cancer are faced with more challenges. When first diagnosed people generally have never heard of their disease. They feel isolated so they go away and Google it and then they're faced with complex information, and support isn't at their fingertips. It's my role to help clear the fog of a complex and rare cancer diagnosis, to provide good information that makes sense."

Lynne works at the Christie Hospital and day to day her role certainly keeps her busy. She has a case load of 550 new patients and sees patients in outpatient clinics every day, sometimes all day. Lynne works together with her patients to review their treatment, look at test results and control any symptoms they have. One of her key roles is to help people make choices about their future care and express their wishes.

Sometimes those decisions about the future are hard to make and Lynne plays a central role in helping patients and their families have conversations about what can be an uncertain future. It's clear that Lynne sees this is an important aspect of the care she gives, and one that she doesn't shy away from. "People are complex and how they feel about cancer is complex too. This role is about understanding people, talking about difficult things and asking those difficult questions. Sometimes people get stuck emotionally and they can't move on. Usually people just need to talk if they're feeling low and anxious, and doing that with me can often be enough," she says.

Lynne also helps her patients to undertake advance care planning, which involves thinking about the final months of life, and focusing on the care people would like. "I usually start these conversations early on if it's an advance stage cancer – sometimes at the first consultation, though you have to be guided by what the

patient wants to know. Most people do want to discuss their prognosis, though it can be difficult to talk about end of life, especially if someone is still having some treatment," she says.

Of course, cancer doesn't only affect the person who has it; it affects family and friends too. Supporting partners and families to cope with the impact of treatment, and the prospect of losing their loved one, is one that Lynne thinks could be done better. When asked how well families are supported, she says, "Sometimes care for the carer is lacking and here at the business end of cancer treatment, I would say it's one of the things we could improve on. We have a Maggie's Centre and that's really helpful; I refer families there to get support. For me, I find it difficult to treat younger patients, especially if they're younger than me. It seems to me that it's often hard to accept in a younger person; they have more roles and more social aspects to their lives, they could be working or have a young family. It feels like a cancer diagnosis like this shakes their identity more."

Supporting people with cancer, can take its toll on nurses too, though Lynne says it's important to be emotionally available, but not become emotionally attached. But that doesn't mean that her patients don't affect her, and how she lives her life. She says, "This job has made me think differently about life, I'm less serious, I take more opportunities when they come my way, I have a positive attitude about living my life."

Lynne recalls one of her patients who provided her with the motivation for adventure. "I remember one young girl with mesothelioma who was dying and we talked a lot together. I kept talking about going travelling and she said, 'Look at what's happened to me, why are you still here, just go!' So I did!"



Matt Schofield is one of Lynne's patients. He talks about his, and his family's, life with cancer and the support that Lynne gives to all of them.

Matt is a busy man. He works as an aircraft engineer, which takes him away from home to London four nights a week. He has a wife and two children in Bolton who he sees at the weekends and a group of mates who he likes to spend time and have a laugh with. It's a full life, but this year has seen an unwelcome addition: chemotherapy.

Matt was diagnosed with cancer of the bile duct in 2014 when he was just 41. The first symptom he had was jaundice; his skin and the white of his eyes turned yellow. He went first to Royal Bolton Hospital and then to Manchester Royal Infirmary for investigations. "They started doing tests, and they kept doing them. Then after about a week they said they wanted to see me, and it might be a good idea to call my wife and ask her to come in too. That's when I knew something was really wrong. They told me I had bile duct cancer. I don't really remember being told, the world was spinning and I didn't know what to think," he says.

Like many people diagnosed with cancer, Matt had many questions about what would happen next, what treatment he would have and what the future might look like. His consultant had some words of wisdom; take one step at a time. Those are words that Matt has stuck with on his journey through surgery, remission, cancer recurrence and now chemotherapy. Matt explains, "It's become my job, to focus on just one thing at a time. That way things become ordinary and that's how I deal with it. I break life down into smaller things, so I don't have to look at the bigger picture and what the future could look like all the time."

In November 2014, Matt successfully underwent major surgery to have three quarters of his liver removed. He made a quick and full recovery, was home after 10 days and back at work in February 2015. He says that 2015 was 'a gift'. This year the cancer has come back and it is in Matt's lymph nodes and his bowel too.

Matt's care moved from the Manchester Royal Infirmary to The Christie, a specialist cancer hospital. The hospital wasn't what he expected. "The Christie is a very different place from other hospitals," he says, "I was expecting a sad place but it's the opposite. It feels joyous. As patients, we're all in the same boat, so we're not 'special' and all of the staff are there to help you to get the best out of things."

It was there that Matt met Lynne McCallum, his Clinical Nurse Specialist and it's clear how much he values having her there. "When you have a specialist nurse, it's like you stop being just an illness and become a person again. Lynne is pivotal, and the contact with her is hugely important. She is the first person I speak to when I need something. When I first met Lynne, she said I could email her at any time. So, if I wake up in the night and I have questions or I'm worried about anything I get in touch and she will get onto it the next morning."

Clinical Nurse Specialists support patients and their families through treatment and life with cancer, and give them the specialist information they need to make important decisions. Lynne has been a consistent and reassuring presence in a life that's now full of uncertainty. As Matt explains, "Lynne really understands the complexity of everything, she answers my questions and she gives me reassurance. She's a friendly face in the crowd. Having a Clinical Nurse Specialist is like having a virtual hand on your shoulder all the time. She gives me confidence."

For Matt, the most difficult part of living with cancer isn't the treatment, it is the impact his illness has on his family and friends. "My wife; she's amazing. She just gets on with stuff and won't let me wallow. But a cloud does hang over you. When she's on her own I know she finds it hard, when the kids have gone to bed and I'm away; that's when she thinks about things."

Matt has two young sons aged 8 and 5 and when he talks about how his cancer has affected them, his worry for them is clear, but so too is his resolve to make life as normal for them as possible. "My boys are the main thing, the younger one doesn't know much about what's happening or say much, but my older boy is different. He was playing a game with a little Hoover and sucking up bugs and he said he wanted to suck all the cancer out of me. I have thoughts about not being here for them, but I do as much as I can now, and I live life every day. And every day I tell them I love them."

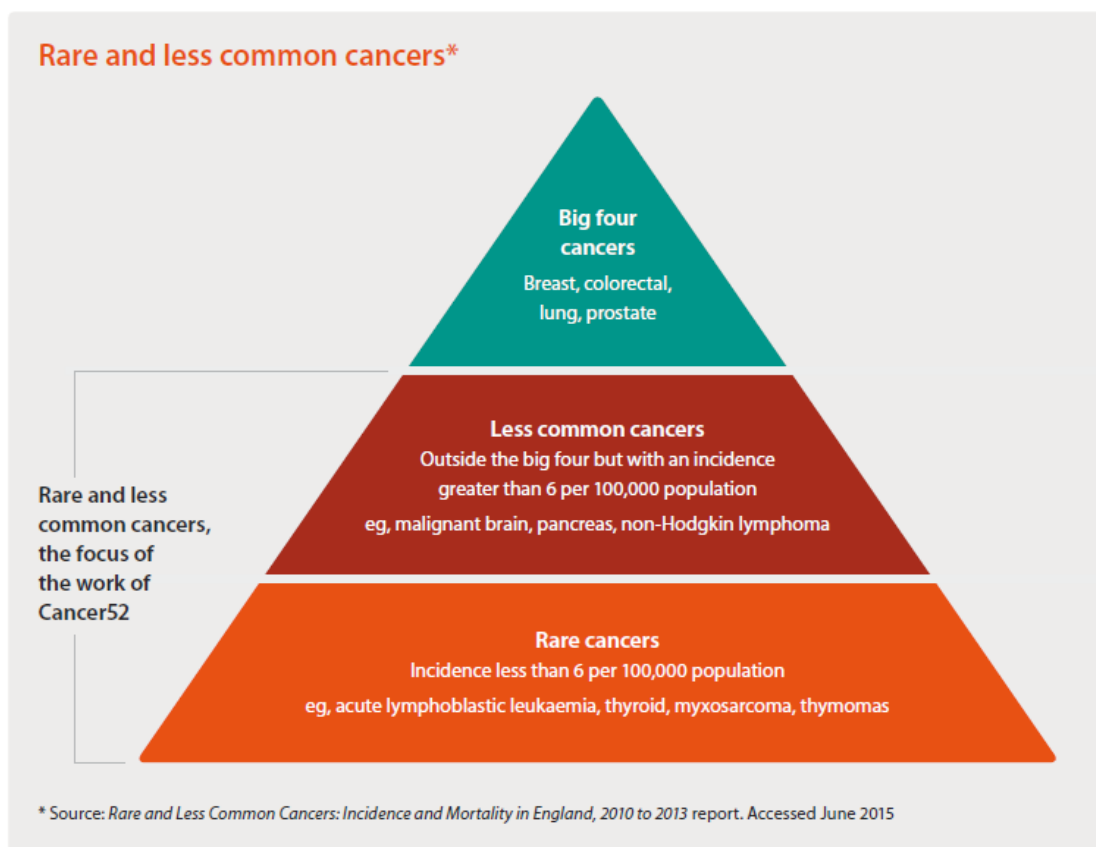
Matt and his family face an uncertain future but he is determined to get on with life. "My wife said perhaps I should think about doing less and being at home more," he explains. "But I said, 'To do what? Sit at home?' If I did that, the kids would know there was something wrong and I want to keep everything as normal as possible. In the end, cancer isn't the be all and end all; living is."

About rare and less common cancers

There are more than 200 different types of cancer. However, there are four types of cancer which together cause almost half (46%) of cancer deaths in the UK – lung, breast, prostate and colorectal cancer.⁵ These types of cancer grouped together are sometimes called ‘the big four’.

Less common cancers are those that are not one of ‘the big four’ of bowel, lung, breast or prostate cancers but which affect more than six in every 100,000 people. Less common cancers include cancers such as uterus, ovary, melanoma, kidney and cervix, as well as those listed above.⁶

Rare cancers are those that affect fewer than six people in every 100,000 people and includes cancers such as thyroid, myxosarcoma, thymomas, liver, ALL (acute lymphoblastic leukaemia) and bone cancers.⁷



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About Cancer52

Cancer52 represents more than 90 predominantly small patient support cancer charities united by their vision of seeing a better future for everyone affected by the rare and less common cancers, which account for more than half of all cancer deaths in the UK.

Our aim is to promote improved diagnosis, treatment and support for those affected by rare and less common cancers, leading to improved quality of life and increased survival.

We work on matters that impact on the rare and less common cancer community – all cancers outside the ‘big four’ of breast, prostate, lung and bowel.

Supporting Cancer52

If you would like to support the work of Cancer52 please get in touch at:

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Credits

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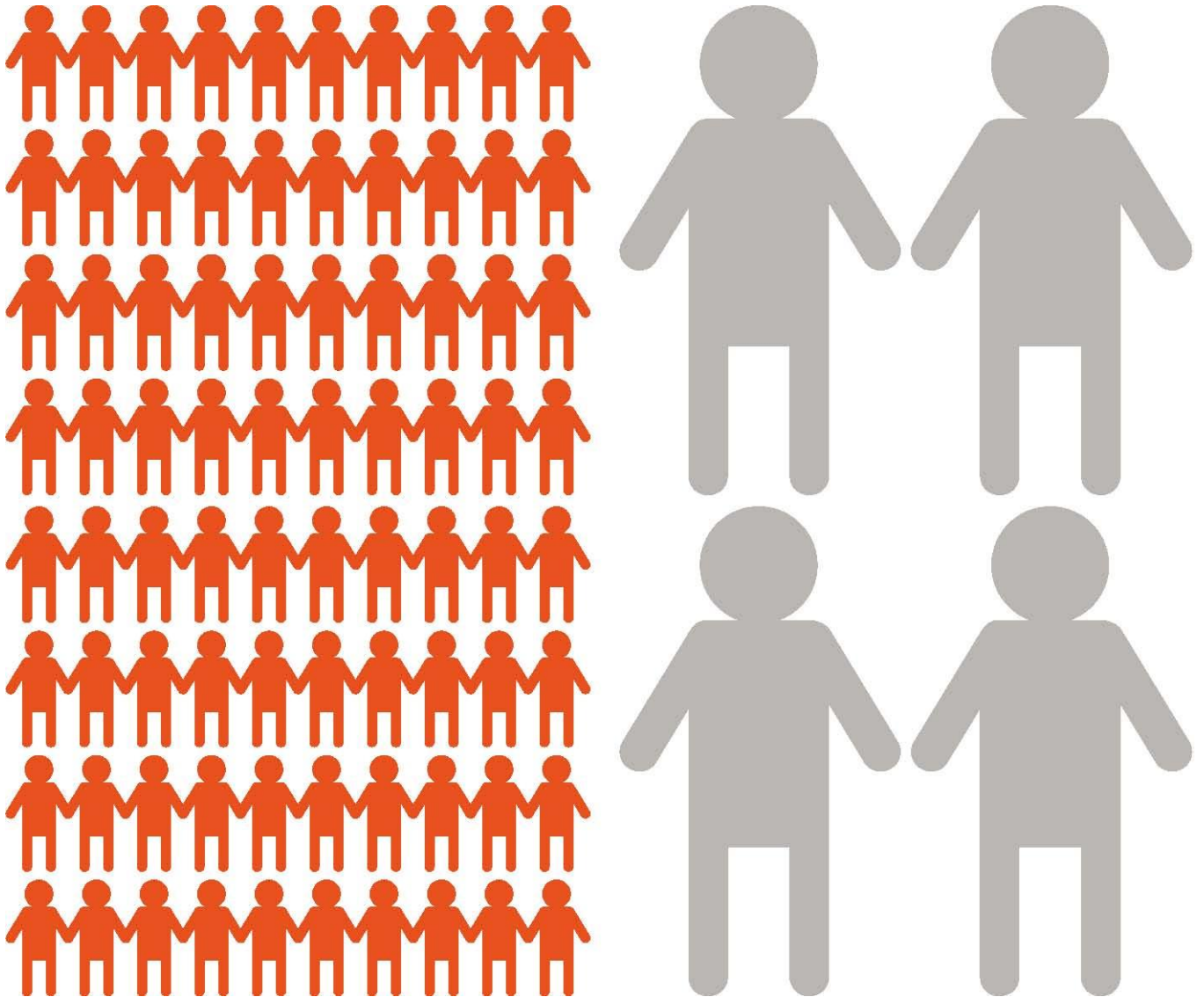
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If we **work together**
we can make as much noise as the big four



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