Every Step of the Way

13 stories illustrating the difference independent advocacy support makes to older people affected by cancer

OPAAL UK
OLDER PEOPLE’S ADVOCACY ALLIANCE

WE ARE MACMILLAN. CANCER SUPPORT
More than one in three of us will get cancer, and for most of us it will be the toughest fight we ever face. People living with cancer are starting down a journey into the unknown. Faced with having to navigate a complex system whilst making speedy decisions about their treatment choices and rights, the experience of accessing health and social care services can be confusing, isolating and frightening. Older patients and carers often experience a loss of choice and control.

OPAAL and Macmillan Cancer Support want to make sure that older people are supported and enabled to exercise their rights, express their views, explore and make informed choices about their care.

In 2011, we began collaborating on our groundbreaking support project for older people affected by cancer. We wanted to explore whether having an advocate – that is someone on your side, to speak up for you, voice your concerns, worries, questions and choices and generally ‘be there for you’ – would help older people better cope with the effects cancer has on their lives, as well as enabling them to access all the health and social care services they need.

In 2012 OPAAL secured funding from the Big Lottery Silver Dreams Programme and Macmillan Cancer Support to deliver a national pilot over eighteen months in Dorset, Stoke on Trent, Gateshead and Southport. We worked with five key partner organisations to recruit and train older people who themselves have been touched by cancer, to provide advocacy support to their peers.

There are many different definitions for advocacy: but older people in the main are unconcerned about definitions, and when faced with cancer they simply need some support. Peer advocates (as the title of this book states) walk side by side, ‘every step of the way’ providing whatever support the older person needs. They aim to be the ‘voice’ of the older person, are non-judgemental and make sure those they support are heard and their views and opinions are acted upon.

The stories in this book belong to real people who we are privileged to work with. They have been offered to us trusting that we will seek a wider audience. We hope to influence both new and existing advocates, enabling them to learn from others experiences and thus promote best practice.

We aim to raise awareness of peer advocacy amongst our health professional colleagues so that they can appreciate how this type of support complements the work of nurses, doctors and all those involved in the care of older people affected by cancer.
Finally we hope to encourage commissioners and funders of cancer support services to recognise the value of advocacy in enabling personalised care services for older people.

The stories seek to illustrate the wide ranging issues that affect older people affected by cancer and the nature and types of support offered by advocates to address these. They can’t cover every scenario. However, they do illustrate emotional trauma, anger, isolation, and the incomprehensible disorientation felt by many upon hearing a cancer diagnosis. They reveal real worries concerning caring responsibilities for loved ones, how to cope with the after effects of surgery, how to tell family members, find suitable accommodation, secure benefits, sort out debt, speak with health professionals and for the terminally ill how to plan for the end of life. These are just some of the issues and concerns identified in these stories. There are many others, for cancer can touch every aspect of our lives.

Some issues are resolved easily such as access to benefits or transport arrangements others are complex, take much more time, have several components and require considerable input from our dedicated team of volunteers.

A disturbing theme running through a number of the stories is that of older people who’ve had bad experiences in the “system”. Our advocates tell us that some older people are afraid to relate all of their experiences in detail as they “don’t want to get anyone into trouble” and also do not wish to be able to be identified for fear of reprisals. Likewise a number of older people affected by cancer have declined to make complaints as they fear reprisals or do not wish to sour relations with hospital staff when their treatment is ongoing.

All of our advocates take time to build that all important trusting relationship which enables the older person to confide worries and concerns. It is this trust that forms the basis of the relationship, our advocates understand the impact of a cancer diagnosis on the individual and are able to address worries and concerns with skill and sensitivity. We are indebted to them.

We hope you enjoy reading these stories and take away from them whatever you sought when you opened this book.

Kath Parson
Chief Executive
OPAAL (UK)

Jagtar Dhanda
Head of Inclusion
Macmillan Cancer Support
March 2014

Stories

Brian
No one should face ‘the void’ that I did

Mary
Things got better for me the day Christine was introduced to me

Jim
I have had a big operation and I am alone

Maureen
I’ve got my mum’s determination and I won’t give up

Ron
I will not have to go to another appointment alone

Alec
Janet and I are now making plans for when I’m gone

Nina
I didn’t feel like myself at all, I felt turned inside out

John
My wife has found it increasingly difficult to deal with things at home

Elaine
When you say you are going to be there I know you will be

Bert and Gladys
The hospital had wanted to discharge Gladys as soon as possible...

Eleanor
She would help me and guide me in the right direction...

David
I still don’t think I’d be here if I didn’t have the support...

Judith
We dealt with problems as they came up

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The names in the stories have been changed to preserve anonymity except Maureen, David, Judith, Elaine, Eleanor, Bob, Richard, Graham, Christine, Ann, Janet, Marion, Audrey, Kath, Wendy who all agreed that their names and stories could be shared.

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I’m 67 years old and I used to enjoy running a successful business in the motor trade. It was hard work but fun and I was not planning to retire. Over the years I’ve enjoyed foreign travel, sailing and had a very good quality of life. My personal circumstances have changed dramatically, I now live alone in a sheltered flat and can feel lonely and depressed.

I have a supportive family and a small number of good friends but poor mobility has reduced my independence. One of the biggest blows has been losing my driving licence which I have held since I was 18.

My cancer diagnosis has been life changing. My life now consists of watching the TV and looking out of the window of my flat. The minute someone says ‘cancer’ I can’t imagine that anyone doesn’t think ‘When am I going to die?’ I was diagnosed in the March and I thought, ‘This is my last summer’. You wake up every day thinking about it.

I have Myeloma which was diagnosed about 2 years ago. I have mobility issues and a lot of pain as a result of the treatment I have undergone. My medication is causing side effects including putting on a lot of weight. I try to be proactive with my diet to counteract the effects. I see my consultant regularly and she liaises with my GP who is really good and has a lot of empathy.

The Community Assessment and Rehabilitation Team (CART) helped me with mobility issues and the CART worker suggested I might like to find out about advocacy support. The coordinator from the cancer advocacy service called me and came to explain the service. I was introduced to Bob, my advocate, at home by the service coordinator and he has also visited me in hospital. My advocate Bob is easy to chat to, he is very easy going. We met up at my home and have also been out for coffee to the coast which is a place I used to go regularly. I would rate Bob as ‘top of the range’ and I am confident that with any situation he will speak to the right person.

Bob found out about the local Myeloma Support Group and went along with me to one of their meetings. I am now in regular contact with them and attend their meetings when I can. He found out about the local shop-mobility scooters and went with me to try them out. I still need support to do my shopping but it makes it much easier. Bob can help to remind me who is involved in my care I’ve seen so many people that I don’t always know who’s who. I’ve shared a particular issue with my advocate and he’s made me aware of steps that I could take but at present I have chosen not to take the
Brian is very intelligent, friendly and outgoing with a great sense of humour. He can no longer drive and is in constant pain of varying levels and physically weak. He can only walk a matter of yards with the aid of a walking stick or frame. He lives alone in a small communal block of flats and when I first met him had extremely low self-esteem. Although previously very well-travelled and active he felt that he had few future prospects of a happy life. He found his condition very hard to accept and suffered bouts of depression and often became upset when speaking about his situation.

The diagnosis of cancer was incredibly difficult for him to come to terms with. Even though in remission when I met him, it was still hard to bear. He still has a few good friends but is no longer independent so cannot socialise as much as he would like. He spends most of his time in his flat watching TV.

Brian’s cancer is now inactive and in remission for 2 years. He has regular appointments with his consultant and GP, both of whom he has a great deal of respect for.

He speaks very highly of his current medical professionals. A variety of pain relief drugs have been tried and the latest drugs give relief for 12 hours each day as a maximum dose. He sometimes becomes confused and forgetful.

He has sometimes taken the wrong drugs or has forgotten to take them leading to potentially very serious problems. These have included passing out and hallucinations.

I was present at one of these events. I’ve spoken to his nurses, doctors and consultants for his safety when he has taken incorrect medication.

Brian always speaks openly and honestly to me and we have a very good relationship. He knows that I understand him, will help him where ever I can and that I will never impose my views on him. We explore options to overcome problems or achieve things he wants to do.

He loves to have a laugh and a joke too and not always to be reminded of the negative side of his situation.

Fact: Nearly half of people with cancer say they experience depression as a result of their cancer – 60% of whom say they did not receive any information, advice support or treatment!
I am Mary and I am 62 years old. I was married for 40 years but my dear husband passed away 2 years or so ago. He was ill with cancer himself and eventually passed away quite peacefully in the hospice. We had a lovely time together throughout our lives apart from the trauma of losing our son when he was very young. I don’t think that we ever really got over that and we never had more children. It’s the sort of thing that you hear about but never think will happen to you. But it does. I don’t think I was ‘right’ from that moment and my confidence was affected for the rest of my life.

Although we lived in the same area all our lives, we never really made many friends. We did used to go to a social club on a Friday now and again but my husband really wasn’t one for sharing himself with other people and we generally sat alone and listened to the music.

When he died I went to work in a shop and that has kept me going. It’s a supermarket and most of the time I am filling up shelves or tidying things. You don’t really make friends in that sort of part time environment.

I started feeling ill myself some months ago. I developed a bad back with pains and aches and I really didn’t feel quite ‘with it’. I went to the doctor and he said I had a kidney problem. I went to hospital for tests. I really was very nervous of it all as I hadn’t done anything at all by myself for many years.

They found that I had a tumour on my kidney and said that they needed to take it out right away. I was in a right state, but it all happened so quickly that I went along with it in a daze. I think I thought that I was glad that they had found the problem and that I would soon be cured. It was after the operation that more bad news came. I was told that further tests showed that I had lung cancer as well. This news absolutely devastated me and I went to pieces for a while. My doctor felt that I was not dealing with my situation at all well. He contacted the cancer advocacy service, with my permission, and asked if someone could come and see me.

I was visited by Graham and Christine in my home. I am afraid that I got very emotional and I think I spent the first hour just telling them...
about my life story. It just seemed to rush out. I knew I was very nervous but I felt such a relief that I was able to tell someone all about the things that had happened in my life.

I didn’t realise that I was so angry about things and that I was still so upset about my son and husband.

Graham introduced me to Christine. She was to be my advocate. She told me that she had had breast cancer. That made me think that I was talking to someone who understood how I may be feeling and that would understand the procedures that may be happening to me over the next few weeks and months.

I was confused about any treatment that may be proposed. I thought they had told me that I would be having some treatment but nobody was telling me what I was having or when it would start.

I was also having trouble with my finances because I wasn’t getting any benefits although I had had to cut my hours at work.

I was lucky to have a job but illness and other things made it impossible to keep up regular hours. They do let me work a few part time hours even now but I wasn’t even getting enough money to pay the rates and the electricity.

I just panicked whenever I spoke to someone at the benefits office and I didn’t seem to be getting anywhere. They seemed to keep mentioning my husband and I kept bursting into tears. I had been feeling so alone.

Christine started telephoning me from the moment we met. At first the calls were just to check how I was but, then she started to visit and helped me write some letters.

We are still in the early stages of our relationship but she has already started to help me sort out my money problems. I now have some money coming in to help me live and my savings are not getting eaten away.

Christine also came with me to the Doctors and that was very helpful. Perhaps the most helpful thing so far was she has visited the consultant with me.

I now understand that my lung cancer is in a very early stage and that there is no treatment planned at the moment, not because it is too
I am Jim and I am 73 years old. I have lived in the same area all my life. My wife passed away 18 months ago. I live in a small, one bedroomed Housing Association flat which I moved into when my wife died. I have been very happy in this flat and have made it into how I want it.

I love to watch sport on television and have bought myself a large flat screen TV so I can watch football.

I have great difficulty with reading and writing although I don't have a learning disability. I was a bus driver during my working life and use the buses to get around now. I also drive a car.

A year or so ago I was diagnosed with cancer of the throat. I was taken to hospital and given a Tracheostomy. I was in hospital a very long time, or so it seemed to me. It was months.

I began to get really angry and fed up with being in hospital. Five other men who were on the ward had gone home but I was still stuck there. I heard about the cancer advocacy service and a hospital social worker made contact with them.

I was visited in hospital by Chris who introduced me to an advocate called Richard. Richard was only a few years younger than me and he had had cancer himself. His father was Welsh which also helped me feel comfortable with him.

Richard and I got to know each other very well and I looked forward to seeing him.

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Richard and I had a meeting with the hospital social worker and one of the nurses on the ward and I was able to say that I wanted to go home as soon as possible. The hospital wanted to discharge me there but I couldn’t go because I couldn’t manage the tracheostomy and wouldn’t be able to put it back in if it came out in the night.

I was getting very angry because I was told that the district nurses could help me with this but none of them had been trained to do so.
Richard came to see me twice more in hospital. I saw him as someone outside the ‘ring of authority’. No one was telling me anything.

Richard told me that was because he thought that at that time nobody actually knew what was happening in the long term.

The hospital said that I could go to a nursing home and they arranged a meeting for me there. I said it was not what I wanted but I agreed to go and see what it was like. I asked Richard, my advocate, if he would come with me on the visit.

We met there a week or so later and I really didn't like it. Perhaps I was never going to because it was not like home. Richard helped me make my feelings known.

I was feeling very angry all the time. I felt I was not getting my message across and the medical people seemed to have at least 2 plans, none of which were going to work or there were reasons why they couldn’t do any of them.

Richard and I got to know each other very well and I looked forward to seeing him. He understood that I wanted to go home and be independent. I am not quite sure how much Richard had to do with it, but, the district nurses were given a rapid training course in tracheostomy management and I was allowed home. Richard had developed a good working relationship with the hospital staff by then.

The nurses showed me how to manage the tubes and things when I was home. However, the daily visits never happened and I felt very isolated in that respect.

The good thing was that Richard continued to visit me. He helped me get the things in place that I needed. This included getting back into a routine for laundry and one or two others things.

I was really frustrated and angry when I was in hospital. I was angry that I should have been ill and then with all the delay that was going on. Nobody seemed to be taking me serious. I know I was angry and I probably let people know it. I feel a bit sorry for that.

Richard was able to help me see things clearly and he was a great support when they were trying to get me into a nursing home. I don’t need nursing.
I moved to my lovely flat 3 years ago after living abroad and in London and Surrey. My friends describe me as indestructible. I recently celebrated my 70th birthday with family and friends in Tenerife.

When the cancer returned two years ago although it was a shock I focussed on decorating my flat to give me another goal. If I am having a down day I may call my advocate Annie and I also call Macmillan Support Line as they have long hours. My GP surgery has arranged counselling for me. I now belong to a local ladies’ social group, after first going with a friend. I have since been on my own which I thought was brave and really enjoyed the evening when we went out for an Indian meal, we had a ball.

I'm looking to get more exercise and I'm hoping to start a dancing class soon. I've got my mum’s determination and I won’t give up. I think you have to fight for every single thing in life.

In 1990 I was first diagnosed with cancer in both breasts and was treated with chemotherapy and radiotherapy. In 2002 the cancer returned in one breast and I was offered a mastectomy. I requested a double mastectomy as I felt it was better for me. I insisted on reconstruction at the same time and was pleased with the results. I take care of my appearance and it's important to me to feel that I look nice.

In 2011 I was told the breast cancer was back. Two top consultants said they had never seen such a recurrence. It was frightening. I started treatment on a tablet called Letrozole which caused side effects even though I had previously been on another tablet before, Tamoxifen, which caused much less side effects.

I've had many ups and downs over the last two years and I eventually told the CNS (Cancer Nurse Specialist) late last year that I wanted to be on the tablet that suited me better. Since I have changed tablets I have been able to lose some weight.

A friend saw the cancer advocacy service leaflet in her GP surgery and passed it on to me. The service coordinator came to introduce the two volunteer advocates to me at home.

Maureen

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It was brilliant meeting my advocates. The first volunteer advocate was very caring, the second, Annie is very chatty like me and we get on well together personality wise. Each of my advocates has gone with me to hospital appointments and provided transport although I sometimes use the local Neighbour-care cars. Although I don’t need someone to speak on my behalf they were there to hold my hand. My current volunteer advocate Annie reassured me and gave me information on where to get help and what to do when I had a worrying symptom recently.

Since I moved house I have less close girlfriends to share things with and I don’t want to worry my son, he’s family. It has been good to have someone with me. I feel I’m not frightened to tell my advocates anything and everything. They are there for me to talk to about positives and negatives. I know Annie is a very strong lady who also cares and I know that she’s not going to get emotionally involved.

Since I stopped driving it has been more difficult to go out and Annie has helped a lot with that and taken me out for coffee and trips. It helps me a lot to get out. I would like to help other breast cancer sufferers and I hope to do this by sharing my story.

“I tell everyone about the service, I think it’s wonderful and we’re lucky to have it in this part of the country.”
My name is Ron and I am 72 years old. I live alone as my wife died several years ago with breast cancer. I have two grown up children. My daughter lives in London and my son lives in Australia. I don't see them very much as you will understand.

I was diagnosed with prostate cancer some months ago. I had been sent to the Oncology department at my local hospital by my GP. I was given several tests and then told to wait for results.

When the letter came, it said I should take somebody with me. The problem is that I didn't know anyone well enough to ask them to go with me.

I should have realised that I was going to get some bad news by the fact that they did suggest I didn't go alone.

Anyway, I did go alone and yet despite the clues, I was really shocked that I was told that I had prostate cancer.

I went numb and my brain stopped working. It was all in a haze. Later on I couldn't remember anything that the consultant said to me. I know I was given a lot of leaflets because I had them when I got to the car. I don't remember driving home at all.

I felt a great sense of confusion, apprehension and got very depressed very quickly. I couldn't bring myself to look at the leaflets that I was given because the whole idea of having cancer was terrifying and I had this idea that if I didn't look at them, it may go away. Stupid when I look back.

I couldn't even decide if I wanted to tell my children about my illness. I can't really tell you why I felt like that. It may be I didn't want to bother them, or maybe I was trying not to confirm the fact in my own mind. I was frozen and unable to do anything.

I did come across somebody who knew about the cancer advocacy services. They gave me the leaflet and I called for help.

A volunteer advocate called David came along to see me at home. I got on very well with him from the start. He assured me that all the things that we would talk about would be confidential, which was still important to me at that time.

Annie’s view

I’ve enjoyed spending time with Maureen and we’ve had some good laughs

Maureen is a very young minded, well presented lady who is funny with a good sense of humour. She has been through a lot and is remarkably positive under the circumstances.

She is a strong lady and knows what she wants and doesn’t want with regards to her treatment and life in general.

She had recently moved to the area and didn’t know many people and felt in need of support, that’s why she got in touch with us.

I got to know Maureen by visiting, taking her out and generally chatting and listening to her story and concerns.

I always tried to be reassuring, kind and encouraging, just to be there and help where I could. The listening process is very important.

I’ve attended several appointments with Maureen both at her GP surgery and the hospital. I’ve tried to encourage Maureen to make new friends and take up social opportunities she has found out about. I also aimed to help build her confidence around her self-image.

I feel I’ve listened and responded to her needs as much as possible and I’ve tried to be as available as possible to support and listen to her when she has concerns.

I hope I have made her feel more part of the local community. I’ve been there to listen when she needed to sound off to someone.

I’ve enjoyed spending time with Maureen and we’ve had some good laughs. I feel we had quite a lot in common particularly as single parents. I hope Maureen feels that I have helped her and been supportive.

Ron

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David was a really good listener and I was able to tell him my story very easily and without any difficulties. He had had an operation for cancer himself and was undergoing observation still.

We talked for a long time in that first meeting and the longer it went on the more relaxed I began to feel. I was still worried of course but my brain seemed to be starting to think again.

One of the things that David and I decided to do on his second visit was to put together a list of questions that I should ask the doctor at my next appointment.

I realised that I didn’t know anything at all about my illness and any treatment that might be proposed. David offered to go along with me to that appointment and I quickly agreed. I knew that I would probably not ask the questions or remember the answers if I went alone.

In the meanwhile we went through the leaflets that the Consultant had given me and together we got the picture of exactly what it was that I was suffering from and what might be done to help me.

Fact: Around 13% of people aged 65 or over are living with or beyond cancer²

At our next meeting I had moved along far enough to tell David that I hadn’t told my daughter and son about my diagnosis. We talked and I decided that I wouldn’t tell them yet as I wouldn’t be able to answer the questions that they would have for me.

David and I started to look at possible sources of care that I may need. We also looked at various ways that I might be able to make myself more financially secure, or viable, as I was then starting to worry about money. I don’t know why at 72 years old.

He found me the address of various places that offered advice and then helped me write a letter. I don’t have any answers yet but that at least has started that ball rolling.

David came along to the meeting with the Doctor and it was good that he did. Along with the trauma of all that I had been told, I have to confess that my memory has begun to fail me as well. That’s been happening for a few years. David was able to take notes and ask the questions that I was missing on my list. The Doctor was very good as well and he was very patient with me.

It’s all a bit daunting at the moment and I still get in a panic. They haven’t decided what treatment I am going to have and if it will involve
I am Alec. I was born in 1941. I live by myself in a small town. I've lived there since 1976. I don't have any family living nearby. I had become something of a recluse, having lived alone for many years. I had also thought about joining a few clubs or something to try and get myself out a bit.

In 2011 I was suffering a number of symptoms which I didn't understand. These included stiff knees and numb knuckles. I tried physiotherapy at that time but it didn't make much difference. I was still driving my car at this time. I described it as my 'ace card' because it was so important to me.

I was diagnosed with CIDP (Chronic inflammatory demyelinating polyneuropathy) in June 2011 and I went to hospital for tests. I had to go every 6 weeks to receive treatment. This involved having fluids in my arms because I had a blood abnormality.

I was diagnosed with diabetes type 2 in 2013 which was being controlled by diet. However things still didn't get right and I kept losing weight.

In 2011 I was suffering a number of symptoms which I didn't understand. These included stiff knees and numb knuckles. I tried physiotherapy at that time but it didn't make much difference. I was still driving my car at this time. I described it as my 'ace card' because it was so important to me.

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I was diagnosed with diabetes type 2 in 2013 which was being controlled by diet. However things still didn't get right and I kept losing weight.

I want all the answers clear in my own head first. David will be able to help me sort that out. My daughter has a lot on her plate with an ill husband. She won’t be able to come and look after me and I wouldn’t want her to.

I can't explain well enough how much of a difference David has made to my life since that awful day I went to see the consultant. How I wish that I had him with me on that visit. It’s a great pity that a system wasn’t in place that would have told me, and others, about the cancer advocacy service before I went to that appointment. If they know you need a person with you they could put in the letter, a telephone number to call, if you don’t have anybody. Perhaps I may not have taken it up as I have tended to keep myself to myself over the years. Other people may have taken it up. I would have, if I knew then, what I know now.

I went into hospital in September and, on my 72nd birthday, I was diagnosed with pancreatic cancer.

This diagnosis made me realise that I needed help and support.

Living alone isn’t a pleasant experience when you have this sort of news to contend with. I was still hopeful at this time because the Oncology specialist was giving me chemotherapy treatment and I was told that I had a chance of recovery.

The Oncology team had given me a plan that involved me joining local groups. I had been given some leaflets. I had also been told about the cancer advocacy service.

Ron’s case is now closed but was open for 4 months during which there were 4 home visits, 1 meeting and 2 telephone calls made.

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I contacted the number on the leaflet. They said that although the service wasn’t in my area, because I was having my treatment in the area they covered, they would send someone to see me.

Janet and Christopher visited me at home and I was able to tell them my story. I showed them...
the information that I already had and told them what I had been told so far.

Janet, who was to be my advocate, was very sympathetic. She told me that she had many years’ experience of working with people with cancer.

We agreed that she would look into some of the groups that had been mentioned by the hospital team and that she would also contact the Oncology team to clarify one or two things for me.

However, when she came back to see me I had just been given the news that I had secondary cancer of the lungs and I think they said the liver. I was told that I would only have another 6 months at the most to live.

I had been hoping that the treatment might be the answer but now I had a different reality.

The plans that Janet and I had now to make were very different. I told her all about what family I had. I didn’t have a will. Janet and I are now making plans for when I am gone.

We are looking towards appointing an executor and making an appointment to make a will. I am also making my own funeral plans with the help of Janet.

Janet is still looking to find groups that I may enjoy and she is concentrating on that in the New Year. I still have good mobility and she is looking for things that I can enjoy whilst I still have some time left to do it.

Fact: 60% of new cancer diagnoses are amongst older people (65+).
Nina

“I didn’t feel like myself at all, I felt turned inside out”

I’m 69, my two grown up children and grandchildren live nearby. I’m a widow and I live with my very fussy Persian cat. Before my diagnosis I was enjoying retirement and keeping active by walking and cycling, I had never felt so well.

I was diagnosed with breast cancer following a routine scan and have undergone nearly a year of treatment since then including two courses of chemotherapy, surgery and radiotherapy. I feel lucky that the cancer was found. When they say cancer it knocks you flying. I went to the coast with my daughter and thought I’ve got to tell her today, we sat down and had tea and I showed her the letter. She came with me to the first appointment. I couldn’t tell my son for weeks, I just couldn’t get it out, perhaps because we had already lost his Dad to cancer.

I’ve told some of my friends just the details that I want them to know, I probably don’t want to burden them.

I was taking part in a clinical trial during my chemotherapy course. I was glad to take part and the staff said I have helped others by taking part. I asked if the Cancer Nurse Specialist (CNS) could visit me at home as it is quite a journey for me to the hospital and was disappointed when they said no. The Research Nurse suggested I try the cancer advocacy service as it offers visits at home. The service coordinator came to meet me at home and then supported me for a short time, including with hospital appointments before bringing my volunteer advocate Marion to my home to introduce us.

I could share my feelings about the cancer and what has happened to me with the coordinator and Marion more than anybody else. We talked about many things, it wasn’t difficult at all and I knew they were there to support me. Owing to the effects of the chemotherapy I couldn’t carry anything in my head so would forget what was said. I didn’t feel like myself at all, I felt turned inside out. Other side effects meant that I stopped driving and lost the confidence to use the bus and to go out.

I was supported at several hospital appointments and Marion took written notes for me to refer to afterwards. When some friends took me to another appointment they then made notes in the same way for me. When I was offered surgery I felt stunned. Its many years since I had an operation and I wasn’t sure how I would manage at home alone afterwards. My
appointments were sometimes changed or cancelled by the hospital which made me anxious. A receptionist called one day and said I had to go in early the next week as the doctor wanted to speak to me. I thought I had done something wrong and worried about it over the weekend. In fact it was good news.

I had quite long waiting times between my various pre op appointments one day and Marion waited with me in the hospital and helped me to complete the long health questionnaire. When the CNS was showing me the prostheses and asking how I felt about the operation I really felt like the whole thing was happening to someone else. I am not so keen on reading printed information and prefer to talk about things. I’ve been able to say to one consultant who used medical terms ‘Does that mean…?’ to get a better explanation. Before my operation Marion printed a list from the hospital website of what I needed to take with me. She provided me with information on getting extra help at home and meal deliveries in case I needed it after my operation and she also looked into local health walks.

After my operation Marion called to see how I was and found out when I would be going home. I felt more confident with someone behind me. I was quite afraid of one particular health professional and when we went in for the appointment Marion said ‘We’ll do it together’ which helped a lot. I feel listened to. Now I am getting out more, driving my car again and using the bus for local trips.

I had many good experiences when I was treated with care and kindness. On one occasion my GP gave me a cuddle. It meant so much. When talking about the shock of the diagnosis she said I would come to terms with it and you do. Another time a doctor from the hospital telephoned me at home the week after I had been for an appointment just to ask how I was. An older nurse was very reassuring once when I was very concerned about something. I never missed an appointment and always tried to do my best.

I felt at times that the treatment regime was too much to cope with, it makes you feel low. Some nurses are like icebergs when what you need is someone to give you a bit of comfort. I have mentioned to Marion that at least half a dozen times I was spoken to by medical staff in a way that I found thoughtless, abrupt or unkind. These memories have stayed with me. Some remarks about how I was struggling to cope on one occasion made me feel more anxious about going to the hospital the next time. More than once I felt nurses were dismissive about treatment side effects that I was asking about. I know I could follow up these issues but have decided not to.

It is good to have someone else to rely on when you are alone. After my operation Marion said ‘We’ll be there for you’. It gives you a warm feeling someone saying that.

My first impression of Nina was of a rather shy person and not feeling very confident. Her diagnosis had rather ‘knocked her for six’. I was matched with Nina because we are of a similar age, and I would like to think it was also because the coordinator felt I could help give Nina the support she needed to face the future with confidence.

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My name is John. I was born in 1953. I live with my wife who is the same age as me, in fact, we are only a month apart in age. We live in a suburb of a town.

I have been a carer to my wife since she had a stroke when she was in her 30’s. That was a terrible thing to happen to someone so young. It left her unable to read or write and her speech is very difficult to understand.

At the beginning of September of 2013 I was diagnosed with cancer of the oesophagus. For the next few weeks I didn’t receive any prognosis or treatment for this condition. I was told that I would be told what was wrong with me at an appointment with the Consultant due in mid-October at the hospital.

I went to that appointment with my wife. I was told that I had a terminal cancer of the throat. I went quite numb. However, my wife wasn’t convinced. She had been a nurse and some of the things that were being said to me were not quite ringing true with her.

She tried to explain her feeling to the nurse on reception but she just turned her eyes up. My wife noticed that there were 2 appointments for Smith on the same day.

Nina’s case has been open for 8 months, is ongoing, and to date there have been 7 visits, 3 meetings and 13 telephone calls.

I feel she deserves it after such a traumatic cancer experience, an experience that came as a bolt from the blue.
contact Richard after I had been seen. I went to see the consultant again in November. They said that I could go into hospital for an operation.

I am now in the hospital, but, unfortunately, the site of the operation has become infected and it looks like I will be here for some time.

My wife does visit me but it's a very difficult journey for her as it's a long way to go. She does drive but doesn’t find it easy. We have a great deal of problem with communication because I have had a tracheostomy.

I didn’t manage to get around to telling Richard that I was going into hospital before I went. I had told him that I would let him know what was happening but things moved very quickly and I didn’t get back to him.

My wife has found it increasingly difficult to deal with things at home. She seems to be getting letters from the hospital that didn’t make any sense. This was particularly difficult due to her communication problems. She can’t pick up the phone and easily have a conversation with someone. She began to wonder if they were still mixing me up with someone else.

She has also had letters from the benefits department asking me to make an appointment to see if I am still eligible for benefits. She can’t deal with this at all.

However, the good news is that Richard had been made aware of my current position. He has contacted my wife and is going to go and see her this week and help her sort things out. That will be a great weight off my mind. I will be able to concentrate on getting well and not worrying about her and what’s going on at home.

The help from the cancer advocacy service is for people ‘affected’ by cancer and not just those that have it. Richard’s input is of great help. He understands my wife’s condition and makes allowances for her communication problems.

I don’t know how long I will be in hospital but I am very reassured that Richard is going to help at home.

Fact: More than nine out of ten (91%) of cancer patients’ households suffer a loss of income and/or increased costs as a direct result of cancer.¹⁰
Elaine “When you say you are going to be there I know you will be”

Elaine, who has since died, was 58 years old and living alone with no family or nearby relatives. She had long term mental health issues and struggled to cope with the news that her breast cancer had returned after 7 years. She felt it was unfair as she had made an effort to take exercise and eat healthily. She felt very isolated in her top floor flat and most of her friends also had mental health issues. The logistical aspects of attending hospital appointments made her extremely anxious. The symptoms of her lymphoedema caused her discomfort and alarm and she had mental health issues. The logistical aspects of attending hospital appointments made her extremely anxious. The symptoms of her lymphoedema caused her discomfort and alarm and she felt unable to care for herself or her surroundings.

Elaine was originally extremely reliant on others to care for her and help her make decisions. She was understandably very negative about her future and focussed on dying. She underwent a course of chemotherapy for the secondary breast cancer tumour in her arm and then radiotherapy. Her prognosis for the secondary breast cancer tumour in her arm and then radiotherapy. Her prognosis for the secondary breast cancer tumour in her arm and then radiotherapy. Her prognosis changed suddenly when a scan revealed secondary cancer in the brain. She had long term mental health issues and limited her activities. She felt extremely anxious. The symptoms of her lymphoedema caused her discomfort and alarm and she felt unable to care for herself or her surroundings.

Elaine was initially referred by a benefits advisor working for a local cancer charity to support her with transport arrangements for her appointments. Three days after the initial referral I met Elaine in my role as the cancer advocacy coordinator in order to support her at an appointment with the chemotherapy nurse. After that Elaine chose to be introduced to her first volunteer advocate in a local café and then later to Bob, her second advocate, at her home. Bob and I each visited her on numerous occasions at home, in hospital during outpatient appointments and in the two care homes she finally moved to.

We spent time listening to Elaine to understand the nature of her anxieties. On some occasions having someone to listen seemed to alleviate her worries. She said on several occasions ‘I feel that I can trust you’ (meaning the service as a whole). When you say you are going to be there I know you will be’. This was in contrast to how she felt let down by other services. We trod a fine line, trying to help her maintain her independence by using hospital transport and sometimes providing transport when it was really needed. She appreciated this and said ‘Thank you for being so human’. Elaine would have good days and bad days and it was possible to see her one day and find her quite upbeat and to find that the next day she was very down or extremely anxious. We had to ensure she was aware that although the service does try to be as flexible as possible we are not and cannot be on call. Having said this, advocacy support was provided by Bob on any day of the week, on many occasions for several hours at a time. This was welcomed by Elaine as this gave her great comfort and reassurance.

We met several of her friends and acquaintances. She generally chose to have her advocate support her at an appointment instead of a friend. We supported her to decline her friends’ offers of help. Elaine was very sensitive about the way she was spoken to by health professionals and it was necessary to listen to her and respond in a certain way in order not to upset her unnecessarily as she would often dwell on things that had been said. Without taking great care over what you said a single word could be misinterpreted and send Elaine into a panic. On one occasion a taxi did not arrive and her hospital appointment was delayed. Consequently Elaine was terrified that all her future NHS treatment would be cancelled! Her advocate was able to allay her fears and calm the situation. She appreciated how she was listened to and contrasted the interactions with her friends who she described as ‘talking in at her’. She said that she did not find listening and taking in information easy herself especially when she was feeling anxious and felt she sometimes got the wrong end of the stick during appointments. She felt that others didn’t always make allowances for her.

We contacted many people at Elaine’s request; we checked her transport arrangements for every appointment, we arranged for her to join a Christmas meal in the local community, spoke with the housing association site manager about potential help through ‘supporting people’, accompanied her to hospital appointments with chemotherapy nurse, oncology consultant, and radiotherapy consultant, we spoke with her GP and with the palliative care team about her needs and the support they were providing.

Bob supported her in her move to a care home and enabled her to choose her room in advance. He was also with Elaine when she had several radiotherapy sessions, when she received the diagnosis that cancer had spread to her brain and she had months to live and also on the day she died. Bob also supported her special friend in the final few weeks of Elaine’s life and then until her ashes were scattered.

Fact: Older women have been found to wait longer before presenting with symptoms of breast cancer. Late presentation is linked with poorer survival.11

Elaine said that she greatly looked forward to our visits and she maintained close contact with us throughout her final months.

Every Step of the Way
Transport continued to be a source of anxiety throughout and we responded by continuously double checking the arrangements. The original issue developed into many issues around the gap between what she perceived to be her support needs, i.e. 24 hour nursing care and what was available. Where Elaine felt that her diagnosis had been delayed and she had not been treated fairly we explained the options open to her for raising these concerns but she chose not to pursue them.

The hospital initially suggested she have some appointments on a Saturday but this was unsuitable as she felt extremely isolated and vulnerable on Sundays. We therefore supported her to ensure appointments were rearranged for early in the week when she felt that help would be on hand if she were unwell. It was necessary to have long discussions with Elaine about her expectations, how they might differ from reality and the pros and cons of different courses of action. At the appointment with her consultant radiologist her advocate asked on her behalf whether she could be admitted as an inpatient if she felt she could not cope with the daily journey to radiotherapy. This was agreed. She was then admitted but felt that the environment on the ward was not conducive to getting rest. She was then discharged and was not happy about that either. She often needed to vent her feelings about what was happening to her.

Elaine said that she greatly looked forward to our visits and she maintained close contact with us throughout her final months. During this same period she chose not to continue seeing several friends whom she felt did not benefit her. After her move into the care home she felt much less less isolated and less anxious and enjoyed interacting with the other residents. She felt that she had a purpose and was able to help them through talking with them. She also re-found her Christian faith, was baptised and formed a close friendship bond with Bob who also shared her faith.

Elaine acted independently, made several decisions about her care and made arrangements with her solicitor to clear her possessions and close her rented flat. In a matter of a few months Elaine had transformed from a woman in a constant state of anxiety to one who had regained a far greater degree of control of her life and found a purpose to help others. At times, in her final weeks, she said she was “100% happy” and she was anxious that her experiences be used to help others. As a direct result of supporting Elaine we have a better understanding of the complexities of the effects of a cancer diagnosis on someone with pre-existing mental health issues and we aim to continue our learning and are now in contact with our local Mental Health Forum.
My name is Kath. I am Bert’s advocate. Bert is a 90 year old gentleman whose wife Gladys had terminal lung cancer and was occupying a hospital palliative care bed. Bert was quite mobile, still driving but lived some 10 miles away from the hospital. He was undergoing tests himself for prostate cancer and had been informed he’d have to find a nursing home for his wife.

Bert and Gladys had no close family to support them in the decision of which nursing home to choose. Bert wanted his wife to be as near to their home as possible so that he could visit frequently. Bert and Gladys were referred to the cancer advocacy service by the hospital Discharge Liaison Nurse concerned with discharge from hospital palliative care.

My first contact with Bert and Gladys was a visit to the hospital ward where Gladys was an inpatient. Bert was anxious about having to choose a nursing home for his wife for her future care. Gladys had previously had respite in two nursing homes in her area and neither Bert nor Gladys wanted her to move into either of them more permanently. I discussed other options for nursing homes in their area and agreed a date and time to visit a preferred option.

I was able to supply Bert with the CQC (Care Quality Commission) report for the nursing home and gave a leaflet prepared by the advocacy service entitled: “Top ten tips when choosing a Care Home”. The visit was cancelled due to the nursing home having an outbreak of the Norovirus so the appointment had to be rescheduled.

The hospital was eager to discharge Gladys and wanted her to move to any home with a vacancy. I telephoned the Discharge Liaison Team and discussed the fact that Bert and Gladys had a choice in where Gladys went to live. The hospital then agreed to delay discharge until after the visit.

Bert and I visited the nursing home together where, during the visit, it became clear that Gladys would need a wheelchair since the room available was not en-suite. Bert informed the cancer advocacy service by the hospital Discharge Liaison Nurse concerned with discharge from hospital palliative care.

Bert was really appreciative of the support he received.

“Through continuous support our advocacy service provided Elaine with continuity. I visited her at her care home two days before she died and Bob visited her several times in her final week including twice the day she died. Elaine found great comfort in this and in the company of her special friend. She even managed a smile on the day she passed away. We attended Elaine’s funeral and Bob scattered her ashes with a small group of her renewed friends from church a few weeks later.

Although Elaine’s first volunteer advocate was unable to continue supporting her, owing to changes in her own personal circumstances Elaine remembered fondly, asked after her and asked to be remembered to her in the week that she died and I bought and wrote a birthday card for Elaine to send to Bob the week that she died on which she dictated the addition of 6 kisses.

At Elaine’s funeral a friend in her eulogy made special mention of her volunteer advocate Bob and said how much Elaine had appreciated the support and enjoyed the laughter that he had brought into her life in the final months.

The benefits advisor who made the initial referral stayed in touch with us and said afterwards ‘We don’t know what we would have done without your service – it was brilliant’.

Every Step of the Way

Elaine’s case was open for 9 months and during that time there were 28 visits, 9 meetings and over 90 telephone calls.

Every Step of the Way

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Every Step of the Way

Bert and Gladys

“The hospital had wanted to discharge Gladys as soon as possible and was not listening to Bert and Gladys’s wishes”
hospital and I followed this up with a telephone call 2 days later to ensure the referral for a wheelchair had been made.

Bert was satisfied with the nursing home and a discharge date was agreed. Bert felt that he had done his best for his wife and had found a nursing home suitable for both of them in their home town. He expressed his appreciation for the advocacy support and information prior to and during the visit.

As a result of the advocacy support provided both Bert and Gladys were able to articulate clearly where they wanted Gladys to move to, express their wishes and verbalise these. The hospital had wanted to discharge Gladys as soon as possible and was not listening to Bert and Gladys’s wishes. I was able to listen to and express these wishes particularly about location of the nursing home and ease of access for Bert to visit his wife.

Gladys was discharged to the nursing home chosen by an informed Bert having had a choice of two. Unfortunately Gladys died shortly after transferring to the nursing home but Bert felt he had done his best for his wife and was able to easily get to see her and was there when she died.

I was able to make a difference by listening to Bert and Gladys, giving Bert information about the nursing home and supporting him during the visit. Bert was really appreciative of the support he received.
I am in my 60’s which I don’t consider to be old. I have COPD (Chronic Obstructive Pulmonary Disease) and have suffered with numerous chest infections. I have good family support from my daughter, I have two sons who are not around but I am in contact with them. I also have grand children who stay with me regularly. I do talk to my family about my cancer.

When I first had a pain in my back I thought I had bone cancer, having already had breast cancer I was not afraid but it took a couple of visits to the doctor for them to listen. Eventually I was diagnosed with lung cancer. I was confused, did not expect this, and was sure it would be in my bones, this I knew could be treated. I did not know where to turn, money was tight and that was just one of the problems I faced. I had never heard of an advocate except in a court of law. I told a friend who said she had a relative who worked in the cancer advocacy service and she might know what to do. My friend was not sure what her relative did, but she did know she helped people. Through this friend I was contacted and asked if I would like an advocate to visit me in my home if that suited. I thought what is a legal person going to do to help me. That was when I found out what an advocate was; Audrey would help me and guide me in the right direction, she told me how to claim any benefits I was entitled to and also was there if I needed anyone to talk to doctors etc.. We talked about my treatment and the visits to hospital also I feel comfortable with my advocate and know I can say anything and it will be confidential. Still don’t like the name as it reminds me of courts, but what they do is amazing. Audrey listens to me and she was easy to talk to. She still visits me or rings when she can’t.

I appreciate Audrey’s support and visits, her personality shines through – she’s a breath of fresh air!
Eleanor is a very strong person, she is coping with her cancer as well as keeping her family happy. I really do admire her strength. She has a strong family around her. Although she is sad her two sons will not be around she does have contact with them. She just wanted to sort her house out; she wanted to decorate and renew as she is leaving her house to her daughter. This she was able to do with the extra benefits she was entitled to.

She is suffering with lung cancer and it’s terminal. Her treatment this time around is harsh, she is losing more time to the treatment than she is to the cancer. She has decided she is not having any more treatment unless it will give her more time. I have visited her at home and will continue to do so.

I have gained a lot from her and she has made me stronger just by listening to her. She never sits and talks about herself unless I bring up the subject by asking what she has been up to; hospital visits or appointments she is waiting for. She is pain free but struggles to breathe. She still manages a smile.

I still see Eleanor regularly to give my support to her through her good and bad days. I am there when she needs me to help her.

Fact: 13% of older people (65+) in the UK are living with cancer.

Audrey’s view
I have gained a lot from her and she has made me stronger just by listening to her

Eleanor’s case has been open for seven months and remains open at present. To date there have been 4 home visits, 1 meeting and 7 phone calls.

Eleanor is a very strong person, she is coping with her cancer as well as keeping her family happy. I really do admire her strength. She has a strong family around her. Although she is sad her two sons will not be around she does have contact with them. She just wanted to sort her house out; she wanted to decorate and renew as she is leaving her house to her daughter. This she was able to do with the extra benefits she was entitled to.

She is suffering with lung cancer and it’s terminal. Her treatment this time around is harsh, she is losing more time to the treatment than she is to the cancer. She has decided she is not having any more treatment unless it will give her more time. I have visited her at home and will continue to do so.

She was referred to our service through a relative of mine who knew we did something with cancer advocacy. She was worried about how she was going to manage on the money she had as she had lots of things she wanted to do before the cancer stopped her.

When I first met her I realised we knew each other by sight, but not by name. She was ok with this and so was I. We talked about times gone by when we were both younger and got to know each other quite well. She always asks how I am when I go and visit. She never sits and talks about herself unless I bring up the subject by asking what she has been up to; hospital visits or appointments she is waiting for.

I have gained a lot from her and she has made me stronger just by listening to her. She never feels sorry for herself even when the treatment has her down. She still manages a smile.

She has had her money sorted and has done her house the way she wanted. She has had a couple of holidays which is what she wanted. She could have been doing so much if she did not feel so tired. She is pain free but struggles to breathe.

I still see Eleanor regularly to give my support to her through her good and bad days. I am there when she needs me to help her.
I am a 56 year old with several disabilities – cancer being the main one. I am living on my own, was married but separated after being diagnosed with cancer. It was seeing Linda from Macmillan Cancer Support at the hospital that put me in touch with the cancer advocacy service.

The main issues at that point were getting a house and my benefits. Two advocates, Kath and Wendy, came to see me at my son’s flat and highlighted the main issues, the biggest one being housing. With the support of my advocate, the housing situation has now been dealt with, if it had been left to me, with all the forms and meetings, it would not have happened – it was all a problem.

I have lung cancer and everyone is aware there is no cure. You have to live with it in your head – when is it coming back? Support from Wendy, meeting for coffees and at home, phone calls, all help deal with the mental side of things.

The cancer was diagnosed early in 2013. Kath and Wendy meeting me was a good thing, me getting about physically and mentally was an issue. Once I had met them [my son was present for the first visit] I felt comfortable with them and talking to them.

The biggest support was contacting the benefits people given how it is handled by CAPITA. The amount of support from Wendy and Kath on that one issue meant I didn’t give up. Whilst there was support with housing and the forms and ASPIRE housing, there is an on-going appeal about my Disability Living Allowance, however the amount of support for my Personal Independence Payment is the main thing.

There are several issues to deal with but one at a time because when it gets too much my mental state won’t cope. In addition to getting the house, I have had help with furnishings, getting them here, and bringing them in – which all make it more homely.

As an NHS professional, I know what advocacy entails as I had delivered it myself. Everything I would expect has been done and beyond because it’s as if you don’t have to worry about red tape guidelines e.g. visiting someone’s home.

"I still don’t think I’d be here if I didn’t have the support as I didn’t have the fight or the will"
I am 67 and was diagnosed with Lymphoma in the top of my left leg. The diagnosis came about because there was a day when I couldn’t get up out of my chair and my legs had given way. I called my doctor who came to see me at home and sent me straight to hospital in an ambulance. I think he must have suspected it was serious and he told me I had to go in sooner rather than later. They took a bone marrow biopsy with a needle that went into where the cancer was and it was very painful. After the results came back I was sent to another hospital and they gave me chemotherapy, I don’t know how long I had the treatment for but I was at that hospital for 6 months. I was sent back to my local hospital but I developed clostridium difficile and that delayed me being transferred to a nursing home. I was in the nursing home for another 6 months and then I came home with a care package. During this time my son was left running our home and dealing with the finances including paying the bills. He found it very difficult to cope with this and some bills were not paid.

When I was leaving the nursing home I was referred to social services and they referred me to the cancer advocacy service. My advocate came to introduce herself to me and visited me in my own home. She visited me on a number of occasions over the time that she was helping me. We dealt with problems as they came up and I was able to contact her if I needed some help. Since I first met my advocate different issues have come up along the way. My advocate supported me to look at my direct debits and helped me contact the companies I held debts with.

My advocate supported me to provide the local council with financial information so that they could set up a repayment plan following my stay in the nursing home ensuring I didn’t get into further debt.

At one point I was really unhappy with the service provided by my care agency. After talking it through with her and deciding on a course of action, my advocate spoke to the care agency on my behalf and managed to get the issue resolved.
She researched and provided information for me about the probate system as I wanted to apply for a Disabled Facilities Grant but the deeds to my house weren’t up to date.

The issues that my advocate helps me with are on-going but I feel that things are moving in the right direction. I recently fractured my hip which has meant that some things, such as the probate, have been put on hold while I recover. I really feel that with my advocate’s support I have been able to express my views and wishes. My advocate was very helpful in what she did.

Fact: For those that do survive their cancer, their needs after initial treatment (survivorship needs) are often unmet. Judith’s case was open for 12 months, involved around 24 visits and regular phone calls.
Notes


For cancer support every step of the way call Macmillan on 0808 808 00 00 (Monday to Friday, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non English speaker? Interpreters available.

Cancer is the toughest fight most of us will ever face. But no one should go through it alone. The Macmillan team is there every step of the way, from the nurses and therapists helping people through treatment, to the campaigners improving cancer care.

Together, we are all Macmillan Cancer Support.
OPAAL, the Older People’s Advocacy Alliance (UK) is the only national advocacy organisation supporting and promoting the development of independent advocacy in England and Wales. We support over 150 members to deliver a wide range of statutory and non-statutory advocacy services to older people locally.

We work with a wide range of national, regional and local organisations to enhance older people’s voice, choice and control aiming to improve older people’s well-being and quality of life.

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Registered charity number 1090182

We have worked with Macmillan Cancer Support since 2011 on our Cancer Older People Advocacy project. Our popular project blog with more stories and information about our work with older people affected by cancer, including our plans to upscale this work can be found here http://advocacyonthewards.wordpress.com