



Facing Cancer Together

demonstrating
the power of
independent advocacy

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MACMILLAN.**
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OLDER PEOPLE'S ADVOCACY ALLIANCE

Foreword

In 2014, we published Every Step of the Way, a set of patient stories which illustrated the need – and value – of peer advocacy services for older people living with cancer. In this, our second publication, we bring together a further twelve stories of overcoming struggle, loss and anxiety, illustrating a new reality of what older people living with cancer can and should experience.

But these stories also speak to a broader societal truth, and contradict the common narrative that the pressure from an ageing population with increasingly complex needs is overwhelming our health and social care system. At the heart of that narrative is a prejudice that older people are somehow too needy, too frail, too dependent and a burden the rest of society is expected to carry. This kind of prejudice robs older people of voice, choice and control. Advocacy – such as in the stories contained here – seeks to return them.

When we read stories like these, we aren't just reading about the experiences of one older person with cancer; we're also being gifted rich insight on the big challenges facing policymakers, commissioners and practitioners, such as how to deliver high quality, compassionate, person centred care that enables people to be equal partners in their care; and how to tackle marginalisation, social exclusion and uncertainty; and how to manage the impact of cancer on family, or emotional health, or housing. Those challenges are for us all, regardless of age, and the

methods of addressing these challenges, by investing in peer advocacy and support, greater community engagement and creating the motivations of staff to involve patients in their own care have a net benefit for all of society.

Stories are powerful not least because they have the capacity to tell us something about ourselves. The twelve stories chosen here represent the wide range of experience that our advocacy programme has encountered across 1500 plus cases over the past five years. We hope that they most of all resonate as examples of the actual support available to provide reassurance, companionship, dignity and, most importantly of voice, choice and control. We want to thank all of those who were willing to share their stories with us, and the many advocates involved in the programme.

Jagtar Dhanda
(Head of Inclusion,
Macmillan Cancer Support)

Kath Parson
Chief Executive OPAAL (UK)

Introduction

Although great progress has been made in developing therapies to treat cancer and **save** a life, much less progress has been made in the UK to **improve** a life affected by cancer: to enable older people to deal with the physical and mental impact of the disease, on both the patient and their loved ones; to get the best out of this treatment; and to gain access to the best care and support. Cancer services are instead typically designed and provided in a clinically focused way, in isolation from the patient's social, emotional and wider health needs, and it is often those who have the most complex needs, beyond just cancer, that are let down by these services.

No two people have the same experience of cancer, but many people share common issues and concerns – these stories demonstrate that having a peer advocate can help on a personalised level, bringing a lived experience to tackle some of the common problems associated with cancer.

A diagnosis of cancer can have an overwhelming emotional impact, not only for the person with the disease, but also for their friends and family. For the person diagnosed, being able to speak with someone is often important, but many people, particularly older people do not want to place this responsibility onto their loved ones. An independent advocate can be vital in this regard, providing independent and non-judgmental support in a neutral setting.

Communication is also important when engaging with health and care professionals. It has been suggested that some older patients may overestimate the severity of the physical impact of treatments, therefore it is important that the correct information about side effects is provided by the clinical experts. However, in many cases information is complex and hard to remember in stressful environments with many people not confident enough to raise questions and deferring to their doctor on decisions about treatment and care, sometimes when this is not best for them. With a peer advocate alongside them, people can be equipped to ask the right questions of their clinician and aided to retain important information.

Cancer treatment can be very debilitating, not just physically, but also practically. For example, the administration of the treatment can involve frequent visits to hospital, so transport becomes a very important factor in getting the right treatment. For some, however, without access to reliable transport and knowledge of local support services, a peer advocate can provide crucial support in gaining access, finding local services and coordinating trips.

Health conditions, caring responsibilities, housing and financial pressures are some of the other factors that can have a huge effect. In many of the cases recorded here, the support that advocates were able to provide to alleviate the pressure from these other issues allowed the participants to cope and self-manage their cancer diagnosis. An example of this is Diane, who lives alone and who has Obstructive Pulmonary Disease (OPD), who is registered as deaf and also

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struggles with reading. Throughout their partnership, peer advocate Andy read letters for Diane explaining them to her, made phone calls on her behalf, set up meetings so that he could be there with her and followed up with Diane and the other parties to make sure everything was clear as to what had to be done. Underpinning much of this: accessing appropriate transport and care support; challenging health professionals; and being encouraged to keep going, is the role of the advocate empowering the person affected by cancer.

Empowerment can often only happen over a longer period of time and through the development of a 1 to 1 relationship. An advocate can quickly improve someone's housing situation by applying for a rent subsidy, however low self-confidence can be the core issue. Many of the advocacy relationships have therefore developed over a number of months, with the cases becoming 'signed off' once the individual is enabled to manage on their own. For example, Joan's story tells us how she was not even able to make a cup of tea when she got home from hospital, let alone care for herself due to inadequate support being in place when she was discharged and it was only through the help of her advocate that she was able to apply for and access applicable social care.

In an era where care must be delivered in a joined-up way, closer to home with fewer resources, solutions like peer advocacy, which tap into the existing lived expertise of individuals to empower people affected by cancer to better manage their illness will be crucial.

No two people have the same experience of cancer but many people share common issues and concerns...

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Albert's story

(not his real name)

I'm 65 and I started using the cancer advocacy service at the beginning of May 2016 and as I write I've been using it for over 2 months. I've had 2 advocates. Sam first came to see me at the Age UK office then she started visiting me at home. I've had a visit every week since then. Now my advocate is Jenny. When she visits I talk about what's happened in the week and what's worrying me. She is a very nice person, easy going. I get on very well with her and she's very understanding. She's had a lot of personal experience of cancer so I know she also understands what I'm going through. We have a good working relationship. The whole thing has been very supportive. It's helping me get through a very difficult time.

Since being told I was dying of pancreatic cancer there has been a lot of uncertainty and confusion. I seem to get more frustrated with people. I don't like people invading my personal space and in the heat of the moment I can get snappy at people. Sometimes I swear, but not at people. I just get frustrated when things don't work out. For example, one time the GP was not available when she had told me she would be. My GP said my reactions might be due to the medication. I talk about this sort of thing to Jenny. She is a good listener and she does what she says she is going to do. Jenny puts herself out for me.

A nurse visits me most weeks. Occasionally she doesn't arrive when I'm expecting her. This is

frustrating and stressful because I wait in all day for her. I also feel rejected. I think this is because of my childhood. Sam has contacted the nurses a couple of times and checked when they are next visiting as I am not on the phone.

Sam phoned my electricity company to check whether they needed a meter reading. Jenny has contacted my housing association to let them know the fire door of the building had been left open. Jenny has also supported me to draft a letter to someone who hasn't been in contact for a while. I wanted to let him know that the reason I didn't turn up to meet him is that I was at the hospital being told that I am dying of cancer. Jenny goes out of her way to make life as easy as possible for me. It takes the pressure off me.

Because of having a learning difficulty and Asperger Syndrome and being brought up in a children's home I have always felt people looked down at me. That's why I get on with Sam and Jenny. I appreciate people not looking down at me. My whole life seems to have been a struggle and sometimes I feel I'm being tested. It's very stressful. I felt I missed out when I was at the children's home due to my learning difficulty. When I was at the training college (a working farm), I had few opportunities with Ford tractors and felt I was not given the opportunities that others were due to my learning difficulty – I felt my learning difficulty always got in the way. I have always had an obsession with Ford tractors. Jenny is helping me to plan a tractor-driving holiday. I feel like I've got a second chance at doing the things I wanted to do.

Sandra's story

(not her real name)

I was 61 when it came. I lost 2 stone in 5 weeks. I was struggling with horrendous night sweats on my own. I used to get drenched all over. It was frightening. I was worried how easily I got tired. I was scared and in pain. It was impacting on my ability to walk but I was still working. When I came back from my morning job I had to lie down and sleep, to give me the energy to get up for lunch. I remember saying to myself "I want out of it". It was so distressing, the pain I was in and not knowing why. I was literally crawling to the bathroom. It was bad for my friends too. I used to be crouched on the floor.

In February 2015, I was referred to a gynaecologist. I had an ultrasound scan. Then I was having MRI and CT scans, all at this time. On my 61st birthday I had a biopsy. The following day it was confirmed: I was diagnosed in March with Non-Hodgkin's Lymphoma. I can't fault the NHS. The following day I had an appointment to see a Clinical Nurse Specialist (CNS). But when a nurse put a board of anatomy in front of me and started describing where it was in my body I found that very difficult. To be the person sitting there, to know you've got it...

On the 16th March, I felt weak and was writhing around in pain. I phoned the CNS. He told me to dial 999. I did. I couldn't manage even a tiny meal. I was taken to Accident and Emergency, then admitted onto a ward. Two days later I started chemotherapy. On the first day of chemotherapy the staff nurse went through the side

effects. It was horrendous. I felt so depressed. It was hard to think straight after having chemotherapy. While I was in hospital, letters were coming from the Department for Work and Pensions asking for sick notes. I didn't earn enough for statutory sick pay. To see my diagnosis written on a form was hard and scary.

Prior to having cancer, I had a good diet, walked everywhere, and was a non-smoker, very conscious of my weight and proactive with my health. This was a complete and utter reversal of everything. I am not a lover of pharmaceutical drugs. I never even used to take pain killers if I could help it. I'd never been in hospital in my life apart from visiting. When I was on the ward the depression started very early. I was in shock. When I was having a bath, I would stare in the mirror. "Is this happening?" I'd ask myself. I knew I wasn't ready to go home.

At the fourth or fifth chemotherapy treatment, a lovely nurse asked how I was coping. She got me a leaflet about The Macmillan Impetus Cancer Advocacy Service. She said "It's a new service, see if it will help". I read it while having treatment.

I needed somebody on my side to understand what I'd gone through and be there to represent me. My CNS was the most difficult person to get hold of. He was lovely but just too busy. I was frightened. I needed reassurance. When I read the leaflet I thought "Ah, somebody to support me".

Sam first came to see me when I was in respite. You don't know what those visits meant to me to discuss ways forward and give me hope. I looked forward to



those visits. I remember the reassurance Sam gave me. We were planning ongoing support while I moved on from respite. It was that link. I was feeling isolated in respite. With Sam coming in it was supporting me. It helped me to have a plan at a point in my life when I did not know what the future held. Impetus and advocacy were my link to help me work out how all the bits were going to come together.

Judith, my second advocate, helped me complete Department of Work and Pensions (DWP) forms. If she hadn't helped me, I'd have nothing financial to live on. Judith saw me really low. With Judith, I felt, "here's someone that knows". She'd been there with cancer herself and been through depression. She was vitally important to me. Because she helped me I was able to be in the support group for Employment Support Allowance. I had to put on the forms about the depression. The cancer was really bad and scary but coping with the depression was a lot worse. Judith helped me through that. She did an awful lot. I shall always be grateful to her. She also helped me with the Senior Housing form. Judith had got through cancer and depression. She became a role model for me. That was a real encouragement.

Rosie, my third advocate is a tremendous support. She has a zest for life and helping others. At appointments, she keeps me on track to target essential things that need to be said. It's hard to speak about cancer. It helps to have a representative. Rosie suggested I make a list for my GP. Health staff are brilliant, but it's the unknown. Rosie is really good. She is brilliant with me. She takes a lot of pressure off me. She told me she'd been through cancer. That has helped me.

“I needed someone on my side to understand what I'd gone through and be there to represent me.”

Susan's story

I was diagnosed with mouth cancer two years ago after finding unusual discolouration and scarring on the sides of my mouth. At the time of diagnosis, I was in extreme shock and the hardest part was having to go under treatment immediately and having really invasive oral surgery.

Because of the type of cancer I had, the treatment plan was a slow process as I had to have multiple surgeries around my mouth and had to have skin removed from other parts of my body to recraft areas around my mouth. I was therefore left with considerable scarring around other parts of my body. The physical and visible changes have greatly affected my confidence and self-esteem. I found that people who once knew me were uncomfortable to approach me because my illness is visible. Also, I myself found it very difficult as I am unable to communicate fully particularly a few weeks after each oral surgery.

I heard of the advocacy service through the local council and contacted them immediately as I was really anxious and worried about a benefits assessment that I had to attend. During this time, I was unable to speak so my advocate Aneesah agreed that we would communicate through text messages. I had my first meeting with my advocate at the office of Independent Community Advocacy Network North (ICANN) and it was the first time that I was able to really reflect on what had happened to me over the past few years. I had just come out of yet another

surgical procedure on my mouth so the bulk of the first meeting was me and Aneesah writing things down and using physical expressions to communicate.

I was extremely emotional because for the first time I really expressed how I was feeling. I felt really vulnerable with the idea of going to the benefit assessment mainly because I would not have been able to communicate my problems on my own.

I felt much more confident knowing that my advocate was going to be with me. During the assessment Aneesah was able to express my daily difficulties on my behalf. With her support, I was awarded the disability benefit which means I don't have to worry as much about my finances and I can concentrate on my recovery.

Due to the nature of my illness I was really struggling to eat and was losing weight. Aneesah also arranged a meeting with my GP so we could discuss liquid replacement meals.

Although I live with my daughter, over the past couple of years I feel that I have become really isolated and lonely. This has had a really big impact on my emotional wellbeing and has made me lose my confidence even more. I have also realised that it would be beneficial for me to meet other people who have had similar experiences to me as I feel that most other people never really understand or are uncomfortable talking to me now.

Since voicing this Aneesah has suggested local cancer support and counselling services which I am planning to attend. I also felt that as a woman my illness has affected my views on my 'physical image'. The stress



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has caused me to have alopecia and this has again had a profound effect on me as I have started to feel really self-conscious. My advocate and I are currently exploring pampering treatments to boost my confidence.

Aneesah's approach was really understanding. I didn't feel that she judged me and I felt very genuinely supported. Because I know she is independent from all the services I really felt that I could just be myself and really be open about how I am feeling. Although I live with my daughter, she is working full time and so I feel that I don't want to burden her with my issues. Therefore, it really helps to have someone who I know is there just to support me.

I feel that advocacy has helped reduce my isolation as I can now access more local services. Because the bulk of my emotional issues have to do with confidence I feel that I am more encouraged by my advocate to remain independent by accessing support. My financial situation has also improved as previously I was in receipt of benefits but with Aneesah's support I am now on the correct rate of benefits. She has always treated me with dignity and respect which again has encouraged me to try and stay positive and motivated. I have felt really comfortable talking to my advocate. I never once felt that I was being judged

Going through what I have done over the past few years has really made me value my health. Prior to my illness I was drinking heavily and smoking. I have now changed my attitude towards how I deal with my problems and Aneesah keeps on reminding me of how proud I should feel for making so much progress in my life!

I feel that I have been given the emotional support to help me move forward with my life.

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“I really felt that I could just be myself and really be open about how I am feeling.”

Charlie's story

(as told by Karen his advocate with input from Pat his wife)

Charlie was referred to the advocacy service by the Macmillan Benefits Advisor. He'd been a hospital inpatient for 9 months as he was still being fed through a PEG (a line straight into his stomach) after radiotherapy to treat throat cancer. He hadn't been able to return home as an appropriate Care Package had failed to be put in place. Although he was free to leave during the day, he had to spend the night on the ward while the liquid feed was slowly fed into his stomach.

Charlie believed that the radiotherapy had 'burned a hole in his throat' and he had wanted to pursue a complaint however his concern proved to be unfounded as this turned out not to be the case. Working with me as his advocate Charlie was able to understand better what was happening and why he was experiencing the symptoms he had. Charlie was also understandably really fed up at being stuck in hospital and wanted to get back to living independently.

Charlie had a long history of alcohol abuse although he had long periods of sobriety. Throughout his adult life he had sustained a relationship with Pat and after his diagnosis she was there to support him. Unfortunately, prior to his diagnosis Charlie had been drinking heavily and found himself in a vulnerable situation where his flat was frequented by (often unwelcome) visitors. Hospital and social services staff judged that neither the location nor the condition of the flat was a

suitable place to be discharged to or for nursing staff to attend. He therefore couldn't be discharged and spent more time in hospital.

Due to his alcohol use, Charlie's memory was very poor and when he was drinking he had been exploited financially by some individuals in his life. As a result, a Power of Attorney was lodged with the local authority and his finances were controlled by a Deputy there.

Pat was keen to support Charlie and as his advocate I quickly got to know them both. Together they were struggling to get things in place to facilitate Charlie's discharge. Pat's flat was too small to accommodate the medical equipment and visiting medical staff that this would entail and she understandably felt unable to take on the medical aspects of his care.

Pat describes Charlie at the point when he was first introduced to me, "He got very depressed. They kept saying they'd release him from the hospital, but it didn't happen. They couldn't sort out his care at home, so they couldn't work out how to discharge him. He couldn't eat, but he could drink alright. He told me he'd had enough."

Charlie's future was far from certain when I first met him, he'd had radiotherapy to treat his throat cancer but there was no definitive prognosis. I attended appointments with him and Pat.

When supporting Charlie at appointments, I was able to remind him about things, ensure hospital transport was in place and I liaised as requested with health care professionals to ensure that he understood what was happening. I ensured he was supported to return



to being able to eat some foods as soon as possible rather than taking all his nutrition via the PEG.

Once Charlie's diagnosis became terminal, the focus of the advocacy centred on supporting him to stay in control of his life right to the end. Charlie desperately wanted to leave hospital and Pat and Charlie wanted to finally get married. I was able to represent Charlie to both the Deputy administering the Power of Attorney and his Social Worker to facilitate not only these wishes but also his wish to die at home.

As Charlie's advocate I helped him and Pat get appropriately graded on the housing list and they successfully bid on a two bedroomed bungalow. When relations broke down with the Social Worker I was able to negotiate on Charlie's behalf so that he no longer had to deal with the individual who had made him feel very judged and misunderstood. When relations also broke down with the appointed Deputy I was able to carry out all negotiations which alleviated some of the stress for Charlie and Pat.

At his request I challenged some of the attitudes Charlie encountered from a number of the health and social care professionals dealing with his case. This meant that ultimately, in spite of them not necessarily understanding his decisions, they did respect them.

Charlie's cancer returned shortly after he had begun to slowly eat solid food again and sadly he passed away in December 2015.

Charlie's wife Pat says, "Our advocate, Karen, helped with such a lot. She used to speak up to the County Council for me, because I didn't want to get into

another argument. She helped Charlie to get to his hospital appointments on time. She'd meet him in Poole to make sure he arrived. I'd have been lost if it wasn't for Karen."

"I'd have been
lost if it wasn't
for Karen."

Suzanne's story

I have lived in Southport all my life and I currently live in communal accommodation with my two cats. I have 3 sisters and a brother and we meet up regularly.

In the spring of 2011 I was about to move into new accommodation with my partner, when I started having trouble with pain in my jaw. My dentist thought it was my wisdom teeth and I was referred for an extraction. Whilst waiting for this appointment, my partner unexpectedly died and I subsequently went on anti-depressants.

In between arranging the funeral and all his administrative affairs, I went for my extraction.

I woke up to be told they'd found white lumps in my jaw, which they'd sent for biopsy. The results came back inconclusive and I had to undergo two more biopsies before they gave me the results and I was informed I had malignant cancer in my jaw, glands and neck. I was in total shock; everything seemed so surreal, I didn't feel I could cope with this and the sudden death of my partner.

In desperation, I turned up at my doctor's surgery. I tried to get across how I was feeling, to the receptionist, but I was told that it wasn't a walk-in centre and I was turned away and they rang me two hours later to come back for an appointment. I found myself wandering around, on Ainsdale beach aimlessly in a terrible state. I didn't know where to turn.

I was admitted for my surgery. I was terrified.

I had part of my jaw and tongue removed. I was then sent for radiotherapy. Unfortunately, this disintegrated what was left of my jaw and I was booked in for a further operation, to replace my jawbone, with a piece of bone from my leg.

Whilst in hospital a neighbour agreed to help me out and feed my cats. I gave him my bank card. I came out of hospital to find that he'd robbed all my money and I contacted the police.

I also received an eviction notice, as if things could get any worse! I was struggling to talk properly and people were struggling to understand me on the phone and seemed to assume I had learning difficulties. I contacted Citizens Advice and they put me in touch with 'Light of Life' who helped sort this out for me.

Feeling at my wits end, I tried to find a free number for Macmillan, as I didn't have much credit and limited funds. I found a free number, but they said they were for fundraising only and gave me the right one to get help, but it wasn't free!

I explained that I now had a looming court case for the theft of my money. I had constant infections in my jaw and I needed to liaise with victim support, I was worried I would be too ill to attend.

It was this lady from Macmillan that put me in touch with Sefton Pensioners Advocacy Centre.

My advocate, Lisa, arranged to meet me at home. She listened to my immediate problem and identified and



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confirmed what I needed her to do for me. We shared our stories of our cancer treatments and she assured me she'd be back in touch as soon as she'd spoken to victim support. I was so grateful and true to her word, Lisa contacted me regularly over the coming weeks, organising statements from my surgeon to send to the court, explaining why I couldn't attend. It wasn't just my infection, but the way I now looked and spoke that I was conscious of. I didn't want to go anywhere, let alone a court room.

Lisa has been great. She liaised between Victim Support and my surgeon's secretary. When the 'not guilty' verdict came through she was able to provide me with the emotional support I needed so much. Lisa applied for a Macmillan grant for me so that I could take taxis to the wellbeing centre. We have plans to go together sometime and I'm looking forward to that. Because I used to be in the armed forces Lisa also contacted Soldiers, Sailors, Airmen and Families Association (SSAFA) for me so they could assess me for further funding.

All of this support has meant that the court case was able to go ahead without me having to be there as a witness. I received the Macmillan grant she helped me apply for which means I don't have to worry about how I am going to get to the wellbeing centre. Going to the centre has been really helpful to me and has boosted me.

I'm still waiting for the SSAFA visit but know that Lisa will support me with that too when it happens. I didn't want to see or speak to anyone, people thought I was mentally impaired when they met or spoke to me on the phone. I needed a voice and Lisa provided that along with the support I needed to regain some of my confidence back.

I can only hope that in the future the district nurses, GP practises and Macmillan make sure that the much-needed information, about places and people to contact to provide much needed help and support are made available from the beginning of someone's diagnosis. I'm really happy about my story being told as this is something I wanted to do. I want people to understand how lost I was before Lisa. Everyone should have access to someone like Lisa. Someone who makes all the difference.

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“I needed a voice and Lisa provided that along with the support I needed...”

June's story

My name is June. I am 71 and always been very independent and worked with young people. I retired at 68 and was very healthy as I had been all of my life.

I started getting occasional blood in my urine which was treated as a urine infection. As it became more frequent my GP advised I should have tests done. I found going to the hospital very scary as this was something I wasn't used too. It was arranged for me to have a cystoscopy, and a biopsy was taken.

Part of me believed I was going to be okay as I was never ill. The waiting was awful as I did have some doubt and was more frightened for my family than myself. When I went to see the surgeon for my results with my daughter and grand-daughter I was told I had a very aggressive cancer of the bladder.

I took the news in my stride but my family were devastated. I was absolutely gutted for them. I was then referred to an oncologist at Clatterbridge Hospital who was wonderful. I call him Mr Medicine. He sent me for various tests resulting in my admission to hospital to have part of the tumour removed followed by chemotherapy.

It was planned for me to have further surgery to remove my bladder, uterus and ovaries. Unfortunately, after a further scan I was told the cancer had spread to my lungs and I couldn't have the operation. Instead I had chemotherapy, trial drugs and radiotherapy. A further planned hysteroscopy was done as they

thought the cancer had spread to my uterus. Luckily it was not cancer but polyps and they were successfully removed. I then had a further CT scan and a consultation to discuss my future.

My consultant was very pleased with my progress. He said he was pleased I had remained so positive and remained living my life as normal as possible. He also said that in the future I would be eligible for further chemotherapy and new trial drugs.

At present, I feel that I am in a very good place because I now get out more. My appetite has improved and the treatment has worked for me as the tumour in my bladder has shrunk. It has also reduced the tumours in my lungs. When I look back, I was told to enjoy Christmas and New Year the best I could.

Whilst I was having chemotherapy a friend advised me to apply for health benefits. After ringing various numbers someone gave me the number for Knowsley Pensioners Advocacy Information Service (KPAIS). It was then that Val, an advocate, explained to me about the Cancer Older People and Advocacy project. She arranged to visit me at home.

Val was helpful and understanding. I went through the issues I needed support with.

I explained that I had rung several other agencies for help to no avail, and that KPAIS was the only one that said they could help me and that they would visit me at home.

Val gave me information on Lyndale cancer support, a local cancer charity support group, and Age UK's cancer support for shopping and cleaning services.

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I was having real difficulties with my mobility and not able to go out as I was becoming very tired and needed to rest. Val arranged for a walking assessment and the day this was carried out I immediately received a wheeled walker with seat and was able to go shopping the same day with my daughter. I received other aids and adaptations to help me around the home and I also got information on will writers.

She then made all of the necessary phone calls and referrals on my behalf and also helped by filling in my benefits form.

From the minute I met Val, my advocate, I knew I was going to be supported. We discussed all of the issues I had and about claiming benefits.

All of my problems regarding services and support were dealt with by my advocate Val and all resulted in positive outcomes. I received an immediate visit from Sue who came back the same day with a wheeled walker to enable me to go shopping with my daughter and to enable me to stop and rest.

I also had various aids around my house which enable me to stay independent. I received Attendance Allowance which helps me to pay for a cleaner and a laundry service. From meeting Val, the process of accessing services was much easier as she did so much for me. Having an advocate means that any problems are not insurmountable.

In having an advocate, I explain that I am given help and support. She's not a legal advice giver. She explains things to others from my point of view. My

family are really pleased that I have someone who is there for me, and if I have any issues my advocate can and will support me.

I now have peace of mind, and a very valuable support who I never want to stop coming to see me. Thank God I met Val and I have her phone number. She will always be there for me.



Tony's story

I was initially diagnosed with prostate cancer a few years ago. However, since then I've also developed colorectal cancer. I was investigated on a number of occasions however no diagnosis was made.

During this time my wife was also diagnosed with dementia and sadly her condition deteriorated rapidly. This was an emotionally turbulent time for me as she was placed in a care home. Due to my wife's ill health and the fact that no follow up was made by the hospital I had assumed that I was just feeling generally poorly and that the stress of what was happening in my personal life was the main contributing factor to my declining health.

However, during a follow up appointment it was established that I did in fact have cancer yet again. The whole experience was really distressing. I was extremely upset and disappointed that my cancer was not identified earlier as I genuinely felt that I did everything I possibly could in terms of attending appointments and not ignoring colon cancer symptoms.

Consequently, I had to undergo surgery where I was fitted with a colonoscopy bag and have had to have numerous cycles of chemotherapy treatment. Emotionally I felt really let down by the NHS as I am of the strong opinion that had they diagnosed me earlier and had my paperwork not been misplaced I may have been treated with chemotherapy alone.

My emotions during this time were a combination of anger and frustration yet I do not feel that I was really able to let this come through as I was fully aware that I had a long journey ahead of me with the recommended treatment. I also felt that I needed to stay strong as my wife was not in a position to really help me emotionally due to her own mental health difficulties. Reflecting back, I now feel that by pushing myself mentally and just getting on with it was actually a blessing in disguise as it meant that I did not allow myself to be drowned by negative feelings.

I became aware of the advocacy service through Macmillan at the hospital. A referral was made and consequently Aneesah contacted me to arrange the first meeting at her office. Because I had significant unresolved feelings caused by missed diagnosis I really wanted this to be followed up legally. Similarly, I lost my faith and trust in the NHS professionals and felt neither confident nor comfortable meeting them on my own. I felt that they have not only failed to diagnose me in time but there was no sincere apology and after going through what I did, I really did not want anyone else to endure the same.

As a result of this my first meeting with my advocate really gave me a platform to openly voice my grievances. My advocate was able to assist me by going through all of my medical records and compiling them together to be sent to a solicitor's firm. This was genuinely a very difficult time for me as I was trying to deal with my own health and simultaneously had to make regular visits to the care home as my wife would get severely distressed if I did not see her on time.



Aneesah attended many hospital appointments with me and supported me through them. These included appointments with my consultant and with my Clinical Nurse Specialist (CNS). As well as my own medical appointments Aneesah was able to ensure I was fully informed when making decisions on behalf of my wife. She was able to support me in discussions about my wife's care. She also helped me write letters and emails.

Advocacy allowed me to take the stress out of the legal procedure I wanted to pursue. Aneesah was able to liaise with the solicitor directly and explain the legal terms and procedures to me.

Unfortunately, my legal case was declined by two separate law firms as they both felt that there was not enough evidence to prove liability on the hospital's part. This was clearly not the outcome I had hoped to achieve however it did help me bring some emotional closure as at the very least I felt that with the aid of my advocate my complaint was pursued.

Moving forward with the assistance of my advocate I became more confident and better enabled to meet with health professionals. I would be encouraged to write a list in relation to my physical symptoms prior to appointments. This allowed me to ensure that all my symptoms would be addressed and that I would leave my medical appointment fully mentally satisfied. My advocate would also attend them with me which gave me reassurance that I had an independent person with me. My advocate would also take notes during the appointments which we would then discuss straight after. This has helped me feel more in control and I feel better safeguarded.

Aneesah was always willing to listen, and as she was independent from other services I felt that I could tell her openly about how I was feeling. I felt that I could call her and this really did help me with feeling less lonely and isolated. She also arranged for me to become more engaged in my local area by teaching me how to use social media and the internet!

With the aid of advocacy, I am now far more confident in liaising with health professionals. My medical treatment has now thankfully been completed and I feel that I have been able to "bring closure to the whole experience" and like I keep telling her I think the advocacy service is "absolutely smashing!"

“My advocate gave me a platform to openly voice my grievances.”

Diane's story

I am a 64-year-old woman and I live alone. Up until my skin cancer diagnosis I travelled around the country on a narrow boat, painting (one of my favourite hobbies) and visiting friends I have made throughout my lifetime.

When I first met Paddy an independent cancer advocate from Sandwell Advocacy I was housebound and in need of a wheelchair to enable me to retain some of my independence. I needed oxygen because of my Obstructive Pulmonary Disease (OPD) and I am registered as deaf and also struggle with reading. I was only able to eat pureed food and needed someone with me to make sure I didn't choke. A far cry from my very self-sufficient and interesting life!

Paddy set up meetings to help me to sort out some financial issues I had with Social Services around my care. He also helped me with a successful grant application to Macmillan Cancer Support so I could buy a wheelchair as I couldn't get one free from the NHS.

It was at this point that I agreed to have a peer advocate. His name is Andy. He, like me, enjoys travelling and has a vast knowledge of the British canal networks. He has had family members affected by cancer so he understands some of the issues I'm facing.

I met Andy and we agreed on fortnightly visits where he would support me with my mobility issues and at meetings with Adult Services and other local authority officers. I've had quite a few issues crop up that I needed support with. It was agreed that if I needed

additional visits this could also be arranged. I was still undergoing treatments and I had fluctuating periods of mood swings and low morale.

One weekend my vehicle was stolen and very badly damaged. Andy was there on hand to support me through this very upsetting time. Shortly after this there was an issue with my oxygen bottles and the frequency of their delivery. Andy was again there to support and reassure me as I felt that this was just one problem on top of another. Andy's ongoing presence and encouragement has enabled me to build my confidence and focus my energies on successfully getting a shower installed in my home.

Throughout our partnership Andy has read letters for me and explained them to me, made phone calls on my behalf, set up meetings so that he can be there with me and followed up with me and the other parties to make sure everything is clear as to what has to be done. I was really grateful for Andy's continuing support through some very traumatic experiences and his input in liaising with statutory sector services at this time proved invaluable.

In the New Year I felt as if everything was getting on top of me again and Andy suggested we sit down together to look at all of my issues and try to prioritise them in order that I could address them in a systematic way.

I had a serious issue with my designated care worker and with Andy's help I was able to employ a new worker and make sure that all the necessary paperwork was completed and that the financial side of things was handled appropriately.



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Sandwell Cancer, Older People and
Advocacy Project

**AFFECTED BY
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WE CAN
HELP**

can provide one-to-one support, help
advocacy for anyone in Sandwell aged 65
has been affected by cancer, either a
parent, family member, friend or carer.

Independent advocate will help you:
 - express your views
 - find out what you want or need
 - get information and explain it
 - access services and benefits you are entitled to
 - make choices and stand up for your interests
 - safeguard your entitlements.



Facing Cancer Together: demonstrating the power of independent advocacy

As a church goer, I have rewarding relationships with many of the congregation and I was recently able to join some of them on a trip to Romania and I was also able to get to a caravan in Stratford upon Avon for a much needed break.

Andy's continued involvement over a wide range of issues has been invaluable and he has been the most important person in my cancer survivorship experience. He supports me at meetings as well as talking through my treatments and their possible consequences which can take me as far away as Leicester. Andy is very flexible and accommodating with regard to visits. He accepts that sometimes although we may have agreed to meet, I am not always in the right frame of mind to talk and he is more than happy to see me at another time.

I have never really trusted services to provide the support that I need and have been cautious in accessing them. Andy's continuing support enables me to get the type of help that meets my own particular individual needs.

“Andy's ongoing presence and encouragement has enabled me to build my confidence.”



Carol's story

I am a 68-year-old widow and live with my 17-year-old Jack Russell terrier. My closest relative who I have any contact with is a niece in Devon.

10 years ago I was diagnosed with a tumour in my pituitary but it was so small then that the advice was to keep monitoring it. I have got another scan next week because it has started to get bigger.

Then 2 years ago, my GP referred me to the Uro-Oncology team at the Churchill Hospital. After an initial assessment I was booked in for a biopsy in November 2014. 3 days before that appointment my husband died suddenly.

I did not attend that appointment, or any of the others which were arranged. Letters arrived from the hospital with new dates and times but I cancelled them all. I could not face doing any of them on my own, without my husband by my side.

I was in quite a bad way but eventually, about a year later, Age Concern referred me to the Hummingbird Cancer Support and Therapy Centre and I have been going there ever since. It was Mechelle, founder of the Hummingbird Centre who referred me to Oxfordshire Advocacy.

My first contact at Oxfordshire Advocacy was Julie who soon arranged for Joanna, my advocate, to come and see me, initially at the Hummingbird. I was not completely sure to start with (I thought Joanna was

Facing Cancer Together: demonstrating the power of independent advocacy

a bit posh) but we soon got to know one another and found we shared a sense of humour. Several members of Joanna's family have been affected by cancer so she understands a bit of what I'm going through.

Since that first meeting in February, Joanna has come with me to almost all my hospital appointments. A PET scan in March showed abnormalities in my thyroid, lungs and kidney and it has been a series of tests, biopsies and consultant meetings since then. Other complications and severe back pain has also meant that I don't always feel that I can undergo the tests or even get to the hospital. Joanna phones me once or twice a week anyway and she calls the hospital if things need re-arranging. I am dependent on volunteer drivers to get there but I am always relieved and pleased to find Joanna waiting for me at whichever hospital entrance she has told me to get dropped at.

If Joanna was not with me, I don't think I would go to these appointments. Even if I did, I would be a nervous wreck. Instead we just seem to chat away while we are waiting and if there is time, we will have a cup of tea afterwards. In the appointment, Joanna takes notes so I can ask her afterwards if there is anything I have not taken in. It's so hard to take everything in at the time if you are on your own. Next week I have got the results of the MRI on my spine and the kidney biopsy. I just don't think I could go on my own and I know I would be much more worried if Joanna couldn't come too. Joanna and I just get on with it and have a laugh (and the odd cry) when we can.

The last eighteen months have been very hard for me. Until I feel stronger, and my health problems are under control, I don't feel up to getting on with my life or making friends without my husband. He was my best friend, but with the support of the Hummingbird and Oxfordshire Advocacy, I feel as if I will one day.

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“If Joanna was not with me, I don't think I would go to these appointments.”



Joan's story

(as told by her advocate)

Joan (not her real name) is a 78-year-old woman who was referred to the advocacy service when she was due to be discharged from hospital. The staff nurse who referred Joan was concerned about her isolation when she returned home. Joan lives on her own in a rural village and has no close relatives. She has a stepson who helps out when he can, but he lives some distance away, works full time and has a family of his own.

Joan has been undergoing treatment for Non-Hodgkin's Lymphoma and she was previously treated for breast cancer. She had also been referred to a Community Psychiatric Nurse as she had been suffering from depression when she was admitted to hospital.

When I went to see Joan in hospital, she said that she expected to be there for some time as she was waiting for a care package to be put in place prior to her discharge and the nurses had told her that this may take some time. We talked about what she might want to do when she goes home and what her interests were; I agreed to do some research about what was available in and around her village.

The following week I phoned to arrange to see Joan again, but she told me that she was being discharged from hospital the next day without a care package as the ward staff had told her she wasn't eligible for support. I agreed to visit her at home to check that she had enough support and to discuss the potential social activities I had found for her.

When I visited Joan at home, she was in a fairly distressed state. Her stepson had prepared for her return home and had made sure that there was food in the house, but she hadn't felt strong enough to even make herself a hot drink; she could not manage a shower and was generally feeling very depressed. Joan was due to have another session of chemotherapy and needed to have a blood test first; she was very worried about how she was going to get to the hospital.

With Joan's agreement, I phoned Social Services and requested an assessment as a matter of urgency; they phoned her back within the next hour and arranged to come and see her. They agreed to look at providing support to have a shower as well as someone coming in at lunch time to ensure she was eating.

I also contacted the patient transport and arranged for her to get a lift to the hospital for her blood test and treatment.

Because she was having to keep the house warm all the time, Joan was worried about the fuel bills. I told her that some energy companies would provide special tariffs for people undergoing cancer treatment; Joan decided that she could manage to investigate this by herself.

We discussed the social activities in the village – Joan was particularly interested in joining a Widows Group which met regularly in the village; I gave her the details for this and she decided that she would ask one of her neighbours to go with her to this.

Joan said that she would be interested in having a befriender, I therefore contacted the new Age UK Burton Befriending Scheme who agreed to arrange for someone to visit Joan as soon as they had trained their new volunteers.

I visited Joan the following week; she said she was feeling much better – she now had support in the mornings and at lunchtime; she was able to wash properly in the mornings and she was eating regularly. She told me that she had managed to get on to a reduced tariff for her fuel bills and this had allayed some of her concerns regarding the bills.

The patient transport had worked really well and she said that she was able to make future arrangements by herself.

Joan had discussed the Widows Group with her neighbour who had agreed to go with her to the first meeting when she was feeling a bit stronger.

Joan had discovered that the reason that she had been discharged from hospital without support was because the hospital records had mistakenly shown her to have a son at home.

I asked her if she wanted support to make a complaint; she said she wasn't sure whether she wanted to do this, so I gave her the contact details of the Healthwatch Complaints Advocacy Service in case she decided she wanted to complain in the future.

Joan didn't have any other outstanding issues, so I closed her case, but told her she could contact us at any point in the future if she wanted further advocacy support.

“When I visited Joan at home, she was in a fairly distressed state.”

Anwen's story

(as told by Angela, one of her advocates)

Anwen (not her real name) was 74 when she self-referred to the Age Connects Cancer Older People and Advocacy project having seen a leaflet in her local cancer specialist hospital. She had been diagnosed with kidney cancer which had now spread to other vital organs.

Initially she wanted support to go and choose a wig. She was scheduled for chemotherapy and knew that her hair was going to fall out. Ideally she wanted a woman to go with her.

The cancer advocacy service was able to provide a peer volunteer advocate called Margaret. She had personal experience of cancer herself having a close friend with breast cancer. Through her friend Margaret learnt about treatment and the effects including sickness, tiredness, shock, anger and how it affects family members and friends. She and Anwen went together and had a successful trip. Anwen got on really well with Margaret and appreciated her support. She described being "over the moon" with the support Margaret had provided.

A couple of weeks later when Anwen had a scheduled hospital appointment she requested that Margaret go with her to provide support whilst treatment options were discussed.

At the same time, Anwen was having Council Tax problems with her Local Authority. Another peer volunteer advocate called David went to see her and

was able to support her to get the matter settled. Again, David had personal experience of cancer having bowel cancer and also prostate cancer. He is not receiving active treatment but is under observation.

In addition to these issues, it transpired that Anwen's family dynamics were fraught. She was sadly involved in a legal tussle with family over her house and her money which was left to her by her late husband.

Peer volunteer advocate David visited her to chat about what support he might be able to provide her with in this situation. It became apparent very early on that Anwen needed someone to talk things through with as she was isolated and estranged from her family.

Her husband had passed away 2 years previously and his children were trying to evict her from the family property. They were also trying to revoke the Will in which he had left all of his money to Anwen.

This was clearly a very stressful and complex situation and it was taking its toll on Anwen's health.

Advocate David was able to assist in looking for a suitable solicitor for Anwen, one who specialised in family law. He was also able to assist in reminding Anwen about her appointments. Where possible David also took her to her legal appointments, going through paperwork to check she understood what her solicitor was doing and that she agreed with his course of action.

There was a great deal of discussion with Anwen about what she wished to do in relation to the home and money which her husband's children were pursuing.

The advocate was also intent on maintaining an impartial role. He explained to her that he could not advise her on what to do since an advocate's role is not to advise. Rather an advocate will gather the information necessary to enable the person they're supporting to make informed decisions.

Anwen was diagnosed with terminal cancer, and was in multiple organ failure; her health was seriously and rapidly declining. Numerous visits were made to her whilst she was at home and also whilst she was in hospital, so that she felt supported and had someone to talk through her concerns with. She did have a son. He, however, had mental health issues and it had been determined by both himself and his mother that he was not in a position to provide her with any assistance.

Whilst she was in hospital, I visited Anwen. By this point she was very poorly. I gained her permission to talk to the ward staff. The ward nurse who was looking after her stated that she was not willing to sign the unified assessment and also they were possibly looking at Continuing Health Care for her as she was nearing end of life care. The nurse also expressed a wish for an advocate to be involved so that they could explain everything to Anwen so that she understood that the medical team were arranging things so that she was in the right place with the right care.

A few days later when peer advocate David visited Anwen again, she was more settled and was comfortable. She had been receiving some physio which she was unhappy about as she felt pulled about and manhandled. David passed these concerns onto the nurse caring for Anwen having gained permission

from Anwen to do so. David talked at length with Anwen about her care and explained in more detail the Unified Assessment and why the nursing team wanted her to sign it. He talked through her pain relief and asked if there was anything she needed. David talked to the staff nurse at length and agreed that he would visit again.

Sadly, Anwen passed away very shortly afterwards and before her issues were resolved.

“Anwen got on really well with Margaret and appreciated her support.”





Barry's story

In late 2015 at the age of 70, I was diagnosed with both prostate and myeloma cancers. This was a very frantic time for both my wife and I especially as my treatment involved a stay in hospital and quite a major operation on my back.

This was a hard time for me but it was even harder for my wife Carmen as she was left alone and isolated. Carmen was put in touch with Jo at Dorset Macmillan Advocacy who called around to see her. Jo helped us get the information we needed to support our application for the housing register. This included her calling my consultant's secretary to agree that he would confirm my health needs.

Carmen was extremely distressed at the thought of me being in hospital in Southampton and not being able to easily visit me. She also worried about how I would cope with the operation, so Jo provided her with emotional support over the phone. Jo signposted Carmen to a local transport scheme and put her in touch with other organisations that could help her.

When I was discharged from hospital we were inundated with appointments for radiotherapy and meetings with consultants and we were suffering from information overload. Once again Dorset Macmillan Advocacy came to the rescue by providing an advocate who would come (and on some occasions take us) to our appointments to take notes about what was said. Our advocate was called Maddy and her help during these first traumatic days was invaluable, she was

always there calm and unflappable and she provided an unobtrusive presence during consultations which left us free to concentrate on what we were being told.

We were given information about a benefits advisor who was able to fill in forms for me which enabled me to claim Attendance Allowance. Without this help I wouldn't have had a clue.

Currently I am undergoing chemotherapy treatment. I've completed the second cycle out of a possible six.

Maddy, my advocate, first came to meet me and my wife at our home. She discussed with us what information we wanted to find out from the various consultations and she agreed to take notes during the meetings. It was agreed that she would prompt us if we hadn't asked all the questions we wanted to. We later discussed the notes she had taken to ensure we had remembered everything and she left the notes with us for future reference.

The consultants we visited were very open to the advocate being present during the consultation and made her feel welcome.

The specific issues have now been resolved. We now have a full understanding of the treatment I will need and we have been signposted to people that can help us with things like benefits and transport. To help us even more, Maddy got us contact details for Myeloma UK so that we could ask to be put in touch with our local Myeloma support group.

I'd say Maddy being there was invaluable and really helped us at a very difficult time.

Acknowledgements

We give our heartfelt thanks to older people affected by cancer who have freely shared their personal stories, allowing us a rare insight into what they've been going through and the impact that both cancer and advocacy have had on their lives.

We also offer grateful thanks to our Cancer, Older People and Advocacy (COPA) delivery partners listed below. They have developed these stories along with the older people they've supported, their peer advocates and their staff.

- Sefton Pensioners' Advocacy Centre (SPAC)
- Knowsley Pensioners Advocacy Information Service (KPAIS)
- Getting Heard Oxfordshire
- Independent Community Advocacy Network North (ICANN)
- Sandwell Advocacy
- Age Connects Cardiff & the Vale
- Beth Johnson Foundation (Staffordshire & Wolverhampton Cancer Advocacy Support Service)
- Dorset Advocacy/Help & Care (Dorset Macmillan Advocacy)
- Impetus (Brighton & Hove)
- Age UK Northumberland
- Advocacy in Barnet.

Our thanks go to all our local and national Cancer Champions as well as to members of our National Health Professionals Board for their continuing support.

Special thanks also to Marie McWilliams OPAAL's Operations Manager for the countless hours spent editing and to Ian McDowell of Patient Powered Medicine for his work analysing the stories for us.

We are extremely grateful for the unwavering assistance of Macmillan Cancer Support both in funding and practical terms. The OPAAL-Macmillan partnership is a best practice example of how great things can be achieved when voluntary sector organisations work together, wholly focused on the benefits to those who use our services.

Thanks also to BIG Lottery Fund's Silver Dreams Flagship Programme which has made this work possible.

With growing evidence of the success of the work that we do, we need to secure more funding to develop additional services in the future. OPAAL's aim is to expand our work in Wales and develop services in Scotland for the first time.

Our ultimate aim is to see every older person affected by cancer living in the UK offered peer advocacy support when and where they need it, regardless of where they live.

If the stories you've read resonate, leaving you feeling you'd like the opportunity to improve the lives of those we support, please do get in touch, there are many ways you can work with us to achieve this. Our contact details are on the back cover.

Kath Parson, Chief Executive, Older People's Advocacy Alliance (OPAAL) UK

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.

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.

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Advocating Change for Older People

OPAAL (The Older People's Advocacy Alliance) is the only UK based national organisation supporting independent advocacy services for older people. We believe older people have the right to independent advocacy support enabling them to exercise their rights, express their views and make informed choices in all aspects of their lives.

We work in partnership with our members to amplify older people's voices, promoting independent advocacy so more people can access it. We also represent member organisation's views to ensure older people's right to access advocacy is accounted for in policy and legislation.

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Our Chief Executive Kath Parson can be reached at kath@opaal.org.uk or by calling 07966 039797

Registered Charity number 1090182

We have worked in partnership with Macmillan Cancer Support since 2011 on our Cancer, Older People and Advocacy programme.

Our popular blog with more stories and information about our work with older people affected by cancer can be found here:
www.opaalcopa.org.uk