Time: Our Gift to You – why cancer advocacy volunteers support their peers
The Cancer, Older People and Advocacy (COPA) programme is different from most other volunteer recruiting services. It has quite specific criteria for those it seeks to recruit. The service is designed to provide peer advocacy support. This means that the majority of volunteers recruited, trained and supported are older people over 50, who have themselves been affected by cancer.

Because of the nature of this group of people it’s more likely that they will present with characteristics not present in the usual cohort of volunteers in the over 50 age bracket. During the course of volunteering they may fall ill again themselves, have to resume caring responsibilities, come up against memories that make it difficult for them to deal with. All of these are very real situations which impact on the volunteering experience and which help place these stories in context.

The stories contained in this publication come from people who have either been directly affected by cancer because they themselves have received a diagnosis or because they have had family members or friends who have been diagnosed.

In the years since 2011 when we first set up COPA, we’ve been blessed to have recruited 263 volunteer advocates and 212 Cancer Champions. Some of them were unable to stay with us for a variety of reasons, as explained above. Others have become stalwarts and continue to champion the cause of peer cancer advocacy tirelessly.

Our peer volunteers tell us there are many reasons why they’ve chosen to become involved with COPA.

“It makes a real difference to those we support. It ticks lots of boxes for me, I wanted to continue to use skill, experience & knowledge to help others, to make a positive difference to people’s lives.”

“I want to help people affected by cancer, and am happy to help people through the ‘cancer experience’. For me it’s all about putting something back, I was well cared for and I’m aware that a lot of other people are not so fortunate.”

“Because I believe I can make a real difference, I can help people practically & personally. I have a good idea of what people are going through. I can help them with their concerns or fears for the future. I enjoy being part of a team, and I enjoy the training offered to us all.”

“I feel I can relate to my advocacy partner very well due to my own experiences. I find it useful to have something in common with my partner in addition to the cancer. I am an empathetic person, a good listener and able to support others to express their concerns and worries.”

In addition to making a difference for others, Cancer, Older People and Advocacy volunteers also tell us they themselves benefit from their volunteering role. They come to the COPA programme with a range of skills, but tell us their involvement often leads to improved people, communication, social and team working skills, as well as improved management and..."
organisational or time management skills. Volunteers also report increased empathy with others and improved confidence in addition to an immense feeling of satisfaction at being able to help others.

Our volunteers benefit from great training and receive support and encouragement from their professional managers, advocates and volunteer coordinators. They support each other and we know they value being part of a wider team.

We hope you find their stories as inspiring and uplifting as we do.

If you’d like to find out more about COPA, where we deliver services and how you might get involved then do contact us. Our contact details are on the back cover.

Kath Parson
Chief Executive OPAAL (UK)
I was diagnosed with breast cancer in 2013 and despite lots of treatment – chemotherapy, mastectomy, radiotherapy, reconstructive surgery and targeted drug therapies – I learnt in 2015 that my cancer had spread and I am now living with secondary breast cancer.

Last year, I decided to volunteer as a peer advocate in Oxfordshire because I could see at first hand, as I was going through my treatment, that there were many people who were struggling to find their way through the healthcare system in our area and to access the support they needed. It seemed obvious to me that a person who has been treated for cancer is potentially in a very strong position to support another person going through the same or similar treatment and experience.

One of the older people affected by cancer that I’ve supported is Sally (not her real name). She was diagnosed with breast cancer in 2015 and was referred to Oxfordshire Advocacy by her specialist breast nurse. Sally lives alone, struggles to get out and had become very isolated and depressed. When I first met her, she talked often about the diagnosis being the “final straw” and I recognised many of the feelings that I had felt when I was first diagnosed: anger, fear, sadness, even despair.

In the first few weeks when I visited Sally at her home, we often would just talk and share experiences and I knew that she really appreciated that someone had taken the time to sit and listen and talk. I knew that when you are first diagnosed with cancer you do get quite a long appointment slot with your consultant and your specialist nurse, but you are in a state of shock and you can’t really take things in, and you are certainly not able to talk through how you are feeling. You need lots of time to process what is happening to you and it is weeks later when you are ready to really think about what is happening to you.

Since then, I have been able to help Sally in a number of ways. For example, I contacted Breast Cancer Care, I knew how good they were from my own experience, and ordered a number of information leaflets for her – some on treatments she had been advised to have, specific information on lymphedema and some on other issues such as her benefits entitlement. Sally suffers from cataracts as well and so I made sure I ordered the information in large print so that she could read the text.

Sally had a specific issue with one of her drugs that was making her feel unwell – I recognised the issue because I had suffered something similar – so I printed some information from the Macmillan Cancer Support website. Sally doesn’t have a computer or access to the internet. I took it to her and read it through for her. I also helped her prepare some questions about this for her next GP appointment and as a result she was able to discuss the issue with her doctor and get the drug changed to minimise the side effects.

Most recently I was able to help Sally with her application for a one-off Macmillan support grant – she wanted to use the money to help with her heating oil. She had been finding it difficult to fill in the form and so she dictated to me what she wanted to say in her application and I was able to write it down for her and I could use my experience to help with the spellings of all the drugs she was taking! She said that receiving the money was very important to her as it helped her worries about putting the heating on in the winter.

I hope that I have managed to convey that working with Sally has also been very rewarding for me. Cancer treatment is often quite technical and complicated and over time you are forced to become quite an expert in the healthcare system and how to get support. I am really glad to be able to put my experience to good use.
Hello my name is Rod and I have recovered from cancer. I was diagnosed with testicular cancer. It was a bit of a surprise but when my wife told me that my left testicle felt like a walnut I thought I’d better get this checked out.

I had surgery to remove the testicle, a very quick operation by the way, and it only took a day before I was walking around again. What I found most difficult to deal with was waiting to find out, I found that more difficult than the treatment. I eventually went to see the consultant and he informed me that the testicle was cancerous and that I would have to undergo a course of treatment.

The treatment made me feel sick all of the time and after the first session I got back home and threw up! They prescribed me a course of anti-sickness tablets but they made it worse! In all honesty I wasn't scared about having cancer, my friends were more worried than I was. Don't get me wrong I wasn't happy about having cancer, but I couldn't change it, I just had to live with it.

Just because you have cancer doesn't mean that how you live your life has to end. Friends tried to wrap me up in cotton wool and protect me. I was a bit physically limited in what I could do (feeling weak all the time) but I wouldn’t let it stop me from going out and enjoying myself.

The consultant said that it was possible that the cancer could spread through my lymphatic system so the course of treatment was short but aggressive. What surprised me the most was still being able to have a physical relationship with my wife, which resulted in the birth of our twins, one of each, I was dead chuffed.

A while later I thought something was wrong again, as I was having constant diarrhoea. Consequently I had an endoscopy, which found nothing, and then a colonoscopy, where various polyps were removed. When I next saw the consultant he informed me that they were in the early stages of change. This time I was a bit worried, as this is what my father had died from. As it turns out I was fortunate, as this was caught early and very recently I received the all clear.

As I'm currently unemployed I have plenty of time to spare. I was looking through the doit.org website and came across the peer advocate position, with Sefton Pensioners Advocacy. Certainly when my father was diagnosed with cancer there seemed little or no help or support, which really hadn't changed that much when I was diagnosed. I felt that through my own cancer journey and other members of my family I had something to offer in terms of support and guidance.

I have had two clients so far and they have very different stories. Although they are my clients I prefer to just think of them as people that I am supporting. They have both been unique, facing different issues and challenges.

One client has already recovered from one form of cancer, only to find out that she has another. There are...
other complications as well, mostly to do with chronic pain, which she is having treatment for. The main issue this lady has is with mobility, as she had no blue badge she found it difficult to get around and as she was limited to where she could park. I successfully applied for her blue badge, which has completely changed things for her, she can now drive to the local village and park outside the supermarket to do her shopping.

She is really, really pleased with this as it has given her a greater sense of freedom. Her details were forwarded to the Department of Work and Pensions (DWP) and now she and her husband both receive Attendance Allowance. Now they can afford to have the house cleaned and garden maintained, which is very important to them both.

My second client has been completely different. He was diagnosed with lung cancer, which had spread to his brain and his diagnosis was terminal. His eyesight was also failing. His behaviour was challenging at times but a lot of this was sheer and utter frustration to where she could park. I successfully applied for her blue badge, which has completely changed things for her, she can now drive to the local village and park outside the supermarket to do her shopping.

He was initially worried about his funeral and also getting in contact with his estranged daughter. On investigation it became apparent that he already had a funeral plan. I helped him to make contact with his daughter again and also arranged for him to have regular communion. During the days before his death he deteriorated drastically, not communicating at all. As he was on morphine every three hours this was hardly surprising.

Although I knew he had terminal cancer I still found it a shock when his nursing home informed me that he had died at 6:30am that morning. There were things that I still wanted to guide him with. I have an immense feeling of frustration that I was not able to help as much as I could, but sometimes things just work out that way. The final thing I could do for him was to make sure his daughter was aware of his final wishes and thus I made sure to communicate these to her. I attended his funeral to pay my last respects.

Advocacy for me so far has been, challenging, frustrating but ultimately rewarding and will continue to be so.

I first visited him in hospital, with a colleague, and his behaviour was challenging. To be fair he had been in hospital for the best part of a month. Eventually he was discharged and he returned home and I was able to support him in terms of getting there, making sure a hospital bed was installed (he had been sleeping on the floor) and ensuring food was delivered (thank you Foodbank). However this only lasted one night and he was then readmitted to hospital. He was then reassessed and admitted to a nursing home.

He was much happier with this as he had the space of the whole lower ground floor and a greater sense of freedom. I was able to support him in terms of getting more clothes and taking him to his property, to help him sort through his important documents and things.

Having retired early after 24 years as a lawyer I wanted to find a volunteering role that would enable me to give something back to society whilst still using the skills gained in my career – such as good listening and communication skills and problem solving.

Whilst still trying to work out exactly what I wanted to do I was diagnosed with breast cancer and underwent chemotherapy, surgery, radiotherapy and immunotherapy over a roughly 12 month period. I was fortunate enough to be given the all clear and turned my attention back to looking at volunteering opportunities but now with an added aim – to see if I could do something positive with my own cancer experience.

That was when I saw the posting for volunteer advocates with the Macmillan Impetus Advocacy Service and it immediately struck a chord. Having been through the cancer diagnosis and treatment journey myself I recognize that we each may have a slightly different response to it (both physical and mental) but there is a level of understanding and empathy that comes from having been through it yourself. Whether that is understanding how difficult it can be to train all the complex information you are being given when you are in shock and frightened or whether it is an appreciation of how sometimes even the simplest of day to day issues in your life can seem overwhelming when you are going through or recovering from treatment.

Being a peer advocate has given me the chance to use my people skills to build a relationship of trust and confidence with a client so that he felt able to speak openly and honestly about his anxieties and hopes for the future in connection with a re-housing issue.

I saw the advantage that a person gets from having someone to talk to who is completely on their side and who is there to help make sure their voice is heard – someone who doesn’t tell them what they ought to do or what is in their best interests but who listens without judgment and helps guide the person to achieving what they want or as near to it as is possible.

In these days of cut backs in social care those service providers are not just short of money but short of time and that is where I have seen advocacy have a real benefit.

My client was in remission from cancer but had ongoing issues which seriously affected his mobility. At the time we started working with him he was living in a adapted two bedroom council house but wanted to downsize as he was now living alone. Because of his concerns about his worsening mobility and anxiety about falling he had requested sheltered accommodation. Having built a trusting relationship with him he felt able to confide in me more and more and knowing to sheltered accommodation was making him feel quite despondent – he thought that was what he “ought to and needed to do” but at the same time was concerned about losing his sense of independence.
As I was able to give him the time and space to talk through all of his thoughts we eventually came up with a plan that met his concerns whilst at the same time preserving his sense of independence.

Part of the problem for him was that he did not have great computer skills so hadn’t really been able to explore fully what options were open to him short of sheltered accommodation – by looking at the relevant websites together he concluded that a ground floor flat with mobility scooter storage coupled with a personal CareLink alarm would be much better for him. However, given he didn’t want to be “any trouble” to anyone and didn’t feel very confident about changing his request, I reassured him that politely explaining his position was fine and we went over how he could phrase it together and left him to think about it.

A few days later when we spoke he told me that he had not only spoken to housing about his new thinking but had actually specified a particular flat that we had seen together on the website which would be ideal. This change in his approach was fantastic and although the flat hadn’t been available at that time his interest had clearly been noted and he was ultimately offered that very flat.

I think that two things really helped him – firstly having someone who had the time to let him get all his concerns and anxieties off his chest and then had the time to help him work out what his real priorities were and order his thoughts. Secondly, just knowing that I was there for him as a support when he needed it made him feel more confident in his dealings with the council.

On a personal level I have benefited a great deal – I feel a real sense of satisfaction and wellbeing knowing that I can make a difference no matter how small to someone else’s life and not only have I been able to use my existing skills I am also learning all the time and continuing to be stretched.

Being a volunteer advocate for the Macmillan Impetus Cancer Advocacy Service has enabled me to achieve my aim of giving something back to the community I live in whilst making use of skills gained in my former career and doing something positive with my own cancer experience. I have a real sense of personal wellbeing from knowing that I can make even a small difference to someone’s life and I can thoroughly recommend it.
I am a 69 year old retired lecturer and manager in further education. I like to keep fit with swimming and cycling and I am a keen member of a local triathlon club.

I was diagnosed with prostate cancer in 2010 and following surgery have been cancer free since. Being diagnosed with cancer is a traumatic experience and most people appreciate the help and support of others, whether they are family, friends or organisations.

I was fortunate enough to have the support of my wife and three children which helped hugely. I was also lucky to be signposted to Prostate Cancer UK, a charity which supports men and their families with information about diagnosis, treatment and the numerous issues you can face post treatment.

Having had this support and personal experience of cancer, I was keen to offer my services as a volunteer. To this effect, for the past four years I have been part of a team of volunteers providing a 1-2-1 confidential helpline to men with prostate cancer. I have also received training and I now man information stands and give presentations at a wide variety of events on prostate cancer.

Over a year ago I saw an advert in our local paper seeking volunteers for an advocacy service for older people and their families affected by cancer. This service is provided in a partnership between Macmillan Cancer Support and Age UK Northumberland.

Not everyone has a person or organisation there when cancer affects them so I thought the advocacy service would fill a much needed gap for those affected and their circle of family and friends. I went along to several training sessions which were really good and I met with other volunteers with a whole variety of experiences of cancer. I was left in no doubt of the need for advocacy services.

I knew myself that my wife had provided ‘advocacy’ support when she accompanied me to my various hospital appointments. She helped me to think through questions in advance of the meetings with consultants. She took notes at the appointments because I was aware that I wouldn’t always remember everything in what was inevitably a situation where I was anxious. This sort of support with advocacy is just one example of what volunteers with Age UK Northumberland’s Macmillan advocacy service do.

The responsibilities of my role to date has varied from helping with housing needs to researching information on all sorts of topics such as Powers of Attorney, housing and welfare benefits. However, generally being a good ‘listener’ and supporting and assisting people in clarifying their priorities is a key part of the role. Not everyone wants to or feels able to talk to people close to them so an independent listening advocacy service can fill this gap for some.

It is extremely rewarding work and most importantly I feel part of a team. I have a lot to learn but one of the
I was looking to do voluntary work and this role seemed to have my name on it. In my professional life I had enjoyed working with people one to one and I felt I might be able to help in this role. I am also able to offer the flexibility that is required and that suits me as well.

I’m a retired health professional and I most recently worked as a health visitor. I have experience of meeting people from all walks of life in all situations including at home. I also worked as a cancer nurse at the Royal Marsden and am interested in developments in cancer care having helped to pioneer the first chemotherapy treatments. I have personal experience of cancer so I have seen it from both sides. When I had my own cancer diagnosis and treatment I was aware how difficult it must be for someone who didn’t know their way around hospitals, appointments, treatment choices etc. It was an upsetting enough time for me but for those less familiar with the environment, particularly older people, it can be a traumatic situation. Often the patient’s family and friends have needs almost as great as the patient and they aren’t necessarily in the best position to be an empathetic supporter to the person.

Keeping a sense of humour, keeping it light, is important and can help in the advocacy role as well. Trying to see the sunshine in every situation is a way of coping, otherwise people can find themselves in a spiral of depression.

Treatment regimens are now much more complicated than 13 years ago. You might need to visit several hospitals to see people with different specialties. You need to keep track of the appointments and sometimes appointments are not properly made and things get forgotten. Having someone to check back strengths of the advocacy project is that I have two excellent organisations in Macmillan and Age UK to back me up when I need it.

I would say to anyone thinking of becoming a volunteer that you will gain much satisfaction along with developing lots of new knowledge and skills and confidence.
with the health professionals and chase things up on the patient’s behalf takes the strain off. People can feel uncomfortable approaching professionals directly and they lack the confidence to challenge things.

To give an example, my advocacy partner was told they were being referred for an urgent scan but when we enquired we found it had not been booked. They were then offered one in several weeks’ time. I went back to the nurse practitioner who checked with the consultant and he had forgotten to make the referral. I am able to trot about in the hospital asking questions when my partner does not have the energy to go to and fro. Taking notes for people during appointments is another useful role to play.

You do befriend your advocacy partner but in a supportive way. You encourage them and champion them. You listen to their point of view and are a kind of sounding board for their frustration and sometimes anger. It can be quite tricky to maintain a distance. It can be tempting to be all things especially when they have no one else. It would be easy for you to do all the things they might want but you know it’s not what the role requires to be effective. It’s important to stick to the advocacy role as opposed to just being a good buddy.

With each partnership the relationship changes from when you first meet them, probably because of their cancer journey and the progression of the disease. As a caring human being you need to adjust the relationship as their needs change, for example, if they become seriously ill. It is hard not to feel quite involved. That is my choice and I know even then that I have to protect myself.

Can you say that as a volunteer you need to be ‘professional’? I recently attended the funeral of one partner because it was at a convenient time for me and also so that I was able to see her husband. Going there provided some closure for me. Everyone is different. What is appropriate in one advocacy partnership may not be so in another. I think it is different supporting a man than supporting a woman. People have different temperaments and there are differences to be seen in age groups.

It is such a privilege to be so involved with people at this critical time in their life. It is quite an honour. Because of my medical background I may know certain things but I am aware that the information should not come from me. It is sometimes difficult but I have to find a way for the person to access the information from the appropriate source.

My hope is that when I have had a chat with my advocacy partner prior to an appointment that they feel able to tell it how it is, hold their head up and remember what they want to say. People do say how much they value having someone with them. Sometimes family members are present and offer good emotional support but the relative may feel equally unable to ask questions of the consultant. They may still be feeling shocked or feel that it is not their place to ask.

I feel that wearing my badge and the green Macmillan lanyard makes doors open. During one partnership I asked to speak with a Ward Sister. Consultants shake
my hand, invite me in and welcome my presence at appointments; in fact, they seem extremely pleased to see me, to know that someone is there to support and interpret for the patient. Consultants will turn to me and ask if I have any questions.

Community care is so complicated. Professionals introduce themselves by their first names and think this is helpful but many older people hate that. Older people affected by cancer can get confused about who is who, several members of staff may have the same first name. They may not know who their named nurse is. Finding a way through the maze is something that advocates can help with.

People assume that cancer treatment is like sailing and a patient will be on a steady course but it’s not like that. Things change all the time – one week a patient is having chemo and the next week they are under the palliative care team. It helps to have someone navigate these rough waters. On top of the people affected by cancer can get confused about who is who, several members of staff may have the same first name. They may not know who their named nurse is. Finding a way through the maze is something that advocates can help with.

The group includes patients, volunteers and health professionals but it is important that the group is chaired by a patient. Above all I enjoy being part of the group. I have met brilliant people and have huge respect for those involved. This gives me additional insight into the work of staff which my role as Chair of Dorset Advocacy’s board does not.

I was diagnosed with cancer about 5 years ago. The set-up of the project coincided with a period when I was looking for some meaningful way to make use of my time, life experience and knowledge. The role of chair of the Local Cancer Champions Board (which we have since renamed as the Cancer in Older People Development Group) reflects my professional background during which I have often chaired meetings. Also at the same time I had joined the Board of Dorset Advocacy one of the service provider organisations.

So it was a combination of circumstances, being in the right place at the right time. I am still in the role of chair after 4 years as the other members were happy for me to continue. I feel that the chair has a key role and I do have a sense of obligation. Coming from a social care background has helped. I can see the importance of the group and what we have achieved in terms of securing funding as well as a forum for stimulating thought and bringing people together. I try to chair the group in a way that is not empire building and I am aware that I am not bigger than the service.

The reward for me is when I get back after going along to an appointment with someone and think that I have made a difference to someone today and how it might have been for them if I had not been there. The people we support understand that we want to be there with them.

I tell my advocacy partners that we get training, support and back up beyond anything I have been offered in my previous professional roles. Being a peer volunteer advocate is a privilege, an honour and a joy.

The motivation I feel to take part comes from knowing that cancer is an awful thing to face especially if you have no one by your side, or even if you do have family but no one able to really help you.

The cancer advocacy service is providing something that people would otherwise not have. There is also an element of self-interest as I may need the service myself someday. If in the future I am unhappy about any aspect of my care I would expect to be able to access this service. Being involved has helped me while I have been coping with ill health and the consequences and side effects of my cancer treatment.

I have been active in the role in addition to attending local and national meetings. I have interviewed staff for the service recruitment. I have attended local external events as a representative of the group including Clinical Commissioning Group (CCG) consultation events. I have also been invited to chair a meeting of the fledging local Cancer Alliance. I have written letters to the CCG and to the funder. I would like to see the steering group develop further. I have also attended volunteer meetings to get to know the peer advocates and support them.
In the broadest context this service provides someone to stand side by side with the person with cancer and stick up for them. My upbringing instilled in me a wish to help others in need.

When I eventually step down from the Board of Dorset Advocacy I may train as a peer volunteer advocate. Although I don’t have the time at present I hope I could do the role as I feel that I can listen quite well and I have worked as a social worker. As well as sitting on the Board of Dorset Advocacy I am also their representative on the local board of the Shared Lives panel for people with learning disabilities.

The impact on me has been very positive. It may sound corny but the role has given me a purpose at a time in my life which could be called a ‘dark period’ in terms of my personal health. The role offers something to look forward to and the demands are not overwhelming.

I can personally identify very strongly with the aims of the service and the steering group and have always had an insight into how much independent advocacy support can be of help to cancer patients and carers. Keeping the steering group going is an achievement in itself. However we are still aiming for the major milestone which will be when this type of support is funded by the health service itself.

The current financial context is difficult and the odds are stacked against us but it is still my aim to see the service integrated into cancer care. I would like to see patients offered access to advocacy support by their GP as well as by hospital clinicians. For some people advocacy support can be as important as the care they might receive from their cancer nurse.
My name is Jim and I have been volunteering with the Sandwell Cancer Older People and Advocacy (SCOPA) project for almost a year. I have recently celebrated my 70th birthday, quite an achievement given that I have been living with cancer myself for several years.

I have many years’ experience of managing care homes in Birmingham and when I retired a year ago I started to volunteer for another organisation but I found that the work offered was not stimulating enough and I wanted something I could get my teeth into. Both of my parents suffered with cancer and I myself know what it is like on that journey so becoming an advocacy partner seemed like a good opportunity to put my experience and skills to good use and keep my brain active.

I also help on another programme at Sandwell Advocacy, monitoring care homes used by the local authority so I spend a fair amount of time with all the staff.

I first met my advocacy partner when she was in hospital. At 81 she had been referred to the service by Hospice at Home and she was keen to find out about cancer support groups in the area. From the start she was clear she wanted support to stay at home. She had declined some treatments and the district nurse was going in.

Her family were around and supportive but she enjoyed having the company of others. She had led an interesting life and had many tales to tell. We walked for miles down Memory Lane recalling her early years and the many jobs she’d had. We chatted for hours in person and on the telephone. She was very clear what she wanted and she was completely accepting of the inevitable.

We were able to discuss treatments, meetings with professionals, decisions to be made and the inevitability of the funeral arrangements. I met with her over 30 times and spoke to her on the phone on a number of other occasions so got to know her pretty well. She very recently passed away in a hospice; they said she had been happy in herself, comfortable, enjoyed being looked after and she rated the food as “first class”.

Her family invited me to the humanist service that she had arranged herself. I was personally thanked for my support and the family acknowledged the great work carried out by the advocacy volunteers at SCOPA.

I thoroughly enjoy the work I do here and am looking forward to supporting someone new in the very near future.
My name is Sherry and I have been a volunteer at Sandwell Advocacy since March 2015. I was a staff nurse for over 45 years and when I retired in 2014 I was adamant I was going to do something productive with my time. I have grandchildren who I adore but having had a very demanding career I wanted to be more than “Nanny” in my retirement. I trained in Chester then worked in plastic surgery, something I thoroughly enjoyed. My final working years were spent as an ophthalmic nurse in Sandwell. Shortly before I retired I was diagnosed with breast cancer, this was a shock to me as I had always attended screening and knew exactly what to look for. I received radiotherapy and chemotherapy and continued to work throughout. I am still under surveillance and attend yearly mammograms but “Once a nurse, always a nurse” and I continue to stay busy. I met Paddy and Juanita from Sandwell Advocacy at a Cancer wellbeing fayre hosted by the Sandwell and West Birmingham Hospitals and they told me about the exciting new project they were working on, supporting people over the age of fifty who are affected by cancer – a perfect opportunity for me to put my skills and experience to good use.

I took part in the training and was soon partnered with a woman who had agreed to advocacy as she had some housing issues. My own experience helped me enormously as I had a good idea of what my partner was going through emotionally and I soon developed an extensive knowledge of housing policy. Although the partnership has ended I feel I have made a very positive contribution to my partners’ journey and she knows she can come back to SCOPA (Sandwell Cancer Older People and Advocacy) if she feels she needs our help again. Throughout my career I had experience of advocates and their role but it has been challenging and very rewarding to be on the other side of the relationship. My knowledge of the NHS and hospital policies has helped me no end and I have enjoyed visiting hospitals with my partner who was not confident in this environment. I was able to ask a lot of questions on her behalf to ensure she was fully able to make informed choices.

I had another partnership with a husband and wife, they also have housing issues although totally different. I have enjoyed running around for them and making phone calls to assist them in downsizing to a more manageable property. They appreciate my matter of fact approach and particularly the fact that I have time, something they haven’t always got. Sadly the husband passed away but the work I put in has enabled his widow to be re-housed closer to her family so that was most beneficial to her. I am now working with a mother and son, she is hearing impaired and her son has learning difficulties.
I have been able to make contact with the necessary agencies to ensure that they are both receiving the right amount of care in order to continue living at home together.

My latest case is very different as I am helping a retired couple find somewhere suitable for them to go on holiday. The wife needs oxygen daily so they needed somewhere that was able to cater for her needs. I liaised with another LCCB (Local Cancer Champions Board) member who pointed me in the direction of a beautiful hotel in Bournemouth which specialises in supporting people with additional medical needs. I really feel as if I am making a difference in my retirement.

I haven’t limited my volunteering to advocacy practice. I have joined the Local Cancer Champions Board as I feel I have professional experience which will benefit the project. I have also ventured down to Vauxhall, People and Advocacy project evaluation and Working Together for Change, a programme aimed at looking at what is and is not working well in the cancer advocacy service. These have drawn on other aspects of my experience.

I would recommend volunteering to anyone like me who wants to give something back. Additionally for any retired professionals who want to do something similar to what they have done as a career, this is an ideal opportunity to be part of a valued and respected team.

If anyone out there is thinking about becoming a peer advocate I would recommend you talk to someone who is volunteering and find out first-hand what it’s like, I think you will get a positive response.

I am a retired Senior Probation Officer/registered Social Worker and left my job as a Family Group Conference Coordinator in March 2014. Approximately a year before I retired I saw an advocate in action, Julie, and was very impressed at how she was able to ensure her client’s voice was heard in a very difficult meeting (child protection issues). At the time I remember thinking ‘I want to do that’ eventually.

So just before I left my work of 33 years I applied to Oxfordshire Advocacy Service, now Getting Heard, and was accepted.

I had missed their community advocacy training but the Cancer Older People and Advocacy project was just beginning and so I was invited to attend that. As a peer advocate I have had experience of a number of friends being diagnosed with cancer including my own mother.

This is where I met Rosie, a fellow advocate and cancer survivor. We hit it off immediately and after this training Rosie asked for her own advocate after a couple of years battling away on her own with lung cancer. I volunteered to be her advocate and was accepted and shortly after we had our first challenge.

The hospital receptionist had phoned Rosie to say she needed to change her upcoming appointment and bring it forward, ‘it was urgent’. Rosie was very distressed as she took this to mean it was bad news. Also, as the new appointment date was fixed on a day I was taking my daughter back to university, I felt very conflicted. However a learning point from this experience was ‘Always have a plan B’.

A fellow peer advocate was available to attend the clinic with Rosie and so this solved the problem. In the meantime Rosie had a GP appointment to discuss this development and thought she could attend on her own. I offered to go with her because I felt they may be able to confirm the worst and I wanted to support Rosie. Rosie kept saying ‘you don’t need to come’, ‘it will be fine’, ‘only if you want to’ etc. Rosie sounded very ambivalent to me and I never believed she really wanted to attend on her own, she never said she didn’t want me to come. So I went with the ambivalence, something I had learned in my training many years ago, and attended with her.

We agreed I would attend her house first to plan for the meeting and what developed was a template for all of our other meetings. I checked with Rosie what she wanted to say, what she hoped to know by the end of the meeting and how I should act if she missed out any of her questions. We agreed I would prompt her if necessary, (my analogy is a sweeper in football), take notes, and if a supplementary question arose, she was okay with me asking it if she hadn’t.

This worked beautifully and as it turned out was a very important meeting as the GP was pretty much confirming what seemed to be ‘bad news’. At the end of the meeting I returned home with Rosie...
and because she thought she had a limited time left, she started to talk about her end of life plan. I felt it was ‘a moment’ and wrote it all down, prompting her about who, what, where etc. It is a wonderful plan, and it felt OK to do it. I think going with the flow covers it. We agreed what I would do with it, type it up, forward it to Rosie who would send it to her brother so he knew what arrangements needed to be made. I felt we had achieved so much in an afternoon as well as really bonded. The irony was that at the rearranged consultant appointment, Rosie was told all was well and not to worry! The rearranged appointment was because the first clinic was booked up and she needed to come to a new clinic, that was it. Little do the hospital administrative staff know about the worry they caused!

I have attended quite a few hospital appointments with Rosie since this and we follow the same routine. It works very well. Rosie is very articulate and wants to do as much for herself as possible so I haven’t needed to make appointments or do other tasks for her.

I have learned a lot from Rosie over the last two years, for example when she was told she needed to now come for annual appointments because her cancer had disappeared, I rejoiced along with our colleagues. However Rosie was feeling very flat about it and was able to tell us that it wasn’t that great because she had felt ‘a crutch had been removed’. She was now having to find a way of living with cancer and it was terrifying.

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There have been other times when as an advocate, supposed there for Rosie, I found myself sucked in. She had been given what seemed to be bad news and was given an immediate solution before we had a chance to draw breath. The hospital registrar kept saying that massive lung surgery was the best, ‘the gold standard’ because it gave a determinate outcome, and that ‘ablation’, the other treatment on offer, was relatively new and was brushed over.

I regained my advocate skills thankfully and asked: what did ‘Rosie want’ and this question helped Rosie gain control of the meeting and she began to ask questions about the less invasive treatment. We called him ‘Dr Gold Standard’ after that and we reflect that if Rosie had not had an advocate with her she may well have been pushed into invasive surgery.

I have other clients who I tend to help with remembering appointments, attending hospital and GP’s and making contact with housing and social services. I feel very valued in what I do, both by the clients and by Getting Heard. In giving up some of my time I find I am continuing to use the skills I have been trained for in my past work and using them and my advocacy skills enables me to help people to get heard, it feeds my strong sense of social justice.

I feel quite privileged to work with my clients, who tell me, directly and indirectly how they find it so helpful and supportive to have an advocate. I feel useful and able to give something back after many years of work. I feel appreciated. I feel very satisfied to be able to make a difference however small, and know that a few people are able to take more control of their lives as a result.

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I have been a volunteer advocate since 2007 when I semi-retired from nursing. I returned to volunteering with Get Heard after cancer and other treatment in 2014, having been inactive since July 2013. The first opportunity I had to get back to volunteering as an advocate was when training came up for the Cancer, Older People and Advocacy project.

During the training I was able to contribute first-hand experience, painfully and tearfully at times but I was undeterred. One word or phrase could have made all the difference to my colleagues’ understanding.

As well as a peer advocate I also became a local and national cancer champion. I was keen that as a cancer champion, my knowledge and understanding might help influence, persuade and campaign locally and nationally.

After training I realised that whilst at 65 have cancer and have had to face appointments, results and complaining about practitioners alone, there are now so many compassionate volunteers who will be there to support others with cancer through those same processes.

As a nurse for 42 years I thought I could empathise. How wrong I was! Nothing can prepare you for the words that tell you, you have cancer. Even worse is the description “cancer victim”. Being a cancer patient means I now understand what that’s like.

It’s strange reflecting on my working life. As a nurse, I was an advocate for my patients, I’ve been an officer for the Royal College of Nursing and have empowered others with the skills and confidence to make a difference. I feel though, that as an advocate with my clients, whilst sensitive to their needs, I am part of a “unique club” who can state it as it is without regret and give them opportunity to express what is deep within their hearts about their thoughts and feelings. That could be about death, pain, family, friends and cancer.

So far I’ve supported 10 older people affected by cancer. Each person is very different, their issues are different and I know I’m making a difference.

Now I ask of anyone thinking they’d like to be an advocate or who think they may already be advocating: Can you really listen carefully and not make any assumptions? Can you accept when a client responds differently to your expectation?

Can you be honest, client-centred, empathic, even when your client’s beliefs aren’t compatible with your own?

Can you accept decisions however bizarre as being theirs alone to choose?

I firmly believe that if you can answer with 60% yes you could become a peer advocate. You’d be joining an extraordinary voyage, you’d be striving for 100%.
I have been a Volunteer Cancer Advocate with the Beth Johnson Foundation (BJF) for just over a year. Following my retirement after 50 years in engineering I felt the need to involve myself with a people-based project benefiting those less fortunate than myself. For the great majority of my life I had enjoyed the best of health, then late in 2009 I was diagnosed with Colon Cancer (at A&E). Emergency surgery removed a malignant tumour. Subsequently I had chemotherapy treatment and continued to be monitored by the oncology department for the next 5 years. Whilst I am obviously relieved that I ‘came out the other side’ I am very mindful of how different the outcome could have been and how difficult coping with the diagnosis would have been without strong family support.

Having spent over 30 years running our family business, I am aware that people-related issues require patience and empathy. I also understand that when people are under pressure they can make bad judgements and inaccurate statements, and I recognise the need for someone able to assist them in clarifying their thoughts.

Being objective and acquiring knowledge to help has become important to me. I spent 18 years as a college governor and a Trustee for a local Engineering Charity. I wanted to use the skills developed over these years and it is against this background I joined the team of volunteers at BJF.

The induction process and subsequent training have been first-class, and the staff are friendly and supportive. My coordinator Collette, and latterly Ruth are approachable and always available to offer guidance. My first client had multiple health concerns, further complicated by his wife being in a care home and he was living in a house with security and maintenance issues. After 2 visits and exchanging numerous emails we were able to present a package of options which would help to improve his quality of life. We were able to involve another agency which supplemented our efforts with regard to sheltered accommodation and benefits assessment. In spite of the complexity of issues a good working rapport was developed. He also had his interest in IT re-invigorated, and was able to convert family photos into digital media to share with his wife. Not all of this client’s issues were resolved but I am happy that we did all we could given that as advocates our role is to enable not enforce.

I have another client who has had considerable difficulties in acquiring an effective healthcare plan, to the extent that we have assisted him in making a formal complaint. I was able to compile and structure the complaint after talking with advisors at the patient support organisation PALS. In this case the client has a supportive and capable wife and I was able probably never achieving utopia, knowing you’ve made a difference and given the most precious gift anyone can receive – your time and support.
to cover a lot of ground through the exchange of emails with attached documentation regarding the history of his prior treatments. Again we were able to offer assistance with regard to benefits and support. Attendance allowance has been granted and backdated.

Prior to our involvement the client had felt abandoned and after our input he feels optimistic that progress has been made. This case is ongoing and I look forward to supporting the client at any subsequent hearing.

Unfortunately not all referrals result in positive outcomes. A recent request for our assistance was made, and in spite of our prompt response, the client passed away before we could develop a plan.

To summarise my first year as an Advocate I feel that I have made a difference, however small, and continue to develop my knowledge and listening skills. The understandable desire to advise has to be suppressed and the ‘knack’ of prioritising issues is developing as I meet new clients and fresh challenges. Our service is enhanced by the excellent partnerships we have developed with other agencies, including the ongoing input from Macmillan Cancer Support.

“The induction process and subsequent training have been first-class, and the staff are friendly and supportive.”
I have been working as a volunteer advocate for seven years. When ICAN (Independent Community Advocacy Network North) began working on the Cancer, Older People and Advocacy project almost 3 years ago, I decided to become involved both as an advocate and as the Chair of the Local Cancer Champions Board (LCCB).

I fitted the person specification in terms of appropriate age and experience as I cared for my father who died of lung cancer over four years ago. He was fortunate compared to many as he had a loving and supportive family. My brother and I were his major supporters and advocates. We accompanied him to all his hospital appointments and I sat with him during each chemotherapy session. We were able to absorb all the information for him, supported him to make some decisions, ask appropriate questions and we provided reassurance and comfort. We also offered support to other family members and each other during an extremely sad and stressful six month period up to his death.

If, as an advocate on the Cancer, Older People and Advocacy project, I can provide some of what I was able to do for my Dad, then I feel I am making a big difference at an extremely difficult time in someone’s life. Each of the clients that I have supported so far have not had sufficient support from family or friends and have, therefore, needed someone on their side to help them through.

Whilst supporting clients I’ve attended meetings, written letters, made phone calls, listened, acted to safeguard, obtained services and much more. I’ve been able to support clients to better understand and access treatment and care services. Clients have been better able to cope and are less isolated as a result of the advocacy support they’ve received.

I’ve been able to ensure that clients are more involved in decision making. I can see them gain confidence because they have advocacy support. Some clients have had support to get their finances sorted out. All in all, advocacy support can improve not only a person’s emotional health and wellbeing but also their quality of life.

Cancer can be frightening and bewildering and for someone with little or no support, having an advocate can make a huge difference to a person’s ability to understand and cope with the challenges they have to face.

I also really enjoy participating in both the Local and National Cancer Champions’ Boards. They have each given me the opportunity to be part of a team. The LCCB gives me access to people from various different organisations and their individual perspectives. I also appreciate retaining some of my existing skills and developing new ones.
I am 56 years old and work at being retired. My journey to becoming an advocate started when both of my parents, within 12 months of each other, were diagnosed with cancer. My mother was first; she took it well, accepted what she was told and understood her treatment choices.

For my father, it was a total shock. He found the round of doctor and hospital appointments confusing. It was difficult for him to comprehend and understand the information given. It was a real eye opener to me and made me see just how hard it must be for elderly people who have little or no support network around them to, deal with this whole process.

When I saw the advert for people to work as an advocate with people who had cancer it seemed an ideal fit. I wanted to help other people to support them, ensure their voice was heard and help them through whatever part of the process I could. I have the time and energy.

One of my first clients was an elderly woman who had previously been treated for cancer of the mouth. Because of surgery, she had some facial disfigurement which bothered her greatly but she had learnt to accept and deal with it. Following a doctor’s appointment, she was told there was a chance that the cancer might come back and she might need further facial surgery.

Knowing what she did, this bothered her. How would further surgery affect how she looked? Would her disfigurement be made worse? Could she lose her teeth this time? How would further surgery affect her being able to eat and drink? Would surgery affect her taste buds? What about her weight? She had already lost a lot and did not want to lose any more.

When discussing these issues, she chided herself saying she was an elderly woman and who would care what she looked like. ‘You care’ I said, ‘a woman’s looks matter, irrespective of her age’. So, I suggested that we come up with a series of questions that were important to her that she felt comfortable to raise and discuss with the doctor and nurse at her next visit before any further treatment took place.

What had I been able to do for her? I had validated that her looks were important and that it was okay to tell the doctor and nurses of her worries about her looks. I had helped to give her a stronger voice, to express her concerns and wishes whilst making sure she felt she was in control of the process.

As a result of the advocacy input, she was better able to cope, felt less isolated and more involved in decision making. I also feel that her quality of life improved and she felt better about herself emotionally.
Matthew’s volunteering story

I was keen to find a volunteer role suitable for me. I thought I could do something meaningful. Being a volunteer advocate appealed to me because of previous work experience. I’m social-work trained and I have a lot of experience and skills to offer.

My Mum died of cancer. I saw how difficult it was for her to live with a terminal diagnosis. Fortunately she had a supportive Macmillan nurse. I have a feeling that I was not there for my Mum as much as I could have been. My brother was by her bedside but I really struggled seeing Mum so ill. I have a sense of regret. It was overwhelming at the time. Being a volunteer advocate for people affected by cancer is a fitting thing to do in my Mum’s memory.

One of the key abilities I use in the role is patience. I draw on life experience. Compassion and curiosity are also qualities I bring to the role. Coping with agencies can be bewildering and intimidating. My client really appreciates the support. I’m calm and realistic, looking at what can be achieved.

My client likes to chat. She trusted me from early on. I was clear about my role and what an advocate can and can’t do. I managed to lay good foundations. I asked what she wanted and that was a constant thing we returned back to. My first task was to talk about her next appointment at the hospital. I listened to my client to work out what she wanted to get out of the appointment. One day I went to visit her and she wasn’t at home. I found out she was in A&E. I managed to find her and talk to her. I contacted her family which was important to her.

By really listening to the client’s views on death and what she wanted, I discovered that a DNR (Do Not Resuscitate) order was written in hospital in respect of her wishes. It was causing distress that she did not have the DNR form at home because she wanted to be sure her wishes would be respected. I helped her to get a copy.

Having a daughter with Down’s syndrome, helping empower people when they are disempowered and find their voice when they are not being heard is very important to me. It makes me feel very proud. A lot of the time people don’t really know what choices they have. I feel useful, very proud. Being an advocate for the Macmillian Impetus Cancer Advocacy Service is a good example of how the community can support each other. Hopefully people would look after me if it was the other way around.

“I have a lot of experience and skills to offer.”
As my retirement from a long career in the Social Care sector was approaching I began to think about how I could continue in some way in this area of work. At several stages of my career I had been involved with the voluntary sector and had met and worked with numerous volunteers so I decided that volunteering was what I wanted to do.

In the summer of 2012 I read an article in my local paper, the Evening Sentinel, about a new Cancer Advocacy scheme that the Beth Johnson Foundation was setting up. I was very interested in this as I had previous knowledge of the Foundation and their excellent reputation for supporting older people. I also had some professional experience of working with and supporting people affected by cancer as well as supporting relatives and friends through their cancer journeys. So I applied to become a volunteer on the Cancer, Older People and Advocacy project and was accepted onto the training course.

My role as a volunteer advocate gives me the opportunity to ‘give something back’ to the community of North Staffordshire. It also enables me to widen my knowledge and experience of advocacy and supporting people not only by direct work with clients, but also by the excellent training courses and the one to one support offered by the project volunteer coordinator and manager.

During the past 3+ years that I have been involved with the Cancer, Older People and Advocacy project I have worked with several advocacy partners. One person whom I especially recall is Victor (not his real name). He was a 70 year old who had been diagnosed as terminally ill with throat cancer. He was single and had no known family. He lived in sheltered housing and he had expressed a wish to make his will and plan his funeral. He had stated that he wanted to leave the whole of his money to the local hospice. The complication for Victor to do this was that he could neither read or write.

My role with Victor was to find out from him if this was indeed what he wanted, to assist him to make an informed decision as to which solicitor he wanted to employ, arrange for the solicitor of his choice to carry out his instructions and plan with the solicitor a practical way of ensuring that Victor could feel confident that his instructions would be complied with. We ensured this by recording the will writing session so that Victor could listen to it as and when he wished. I also discussed his wishes for his funeral with Victor and ensured that these were recorded in his will. I also liaised with the manager of Victor’s housing complex and his support worker. All of these tasks were completed to Victor’s satisfaction.

A few months later I attended Victor’s funeral and was pleased that everything was carried out exactly as he had requested. That gave me a great feeling of ‘job satisfaction’ and the solicitor later thanked me and the Beth Johnson Foundation for the professional and empathic way that our service had been provided for Victor.
Ten years ago I was admitted to A&E following a car accident. My wife and I were shocked to be told that a shadow picked up in a routine x-ray was lung cancer. I was offered the option to have chemotherapy or surgery to remove part of my lung. I opted to have the surgery as I just wanted to get the cancer out of my body. I surprised myself as I didn’t shrink and panic: I became pragmatic and proactive.

I have since had bladder and skin cancer but am in remission and fighting fit. Things have moved on a long way in the past few decades so that a cancer diagnosis is not necessarily the ‘death sentence’ it used to be. I hope that telling my story will enable people to remain positive.

Retirement provided me with the privileged opportunity of being able to ‘give something back’ by volunteering. My own personal experience of cancer and the insight it gives me made Cancer Advocacy the natural option. A lengthy career in the Police Force and a subsequent 28 years as a housing officer also provided me with the skills needed to work with people from all walks of life including the underprivileged and homeless. I think the ability to communicate and be socially adaptable along with a non-judgemental approach is key to building successful relationships with partners.

Not everyone is able to be objective when they are struggling with a diagnosis and I would like to think that my advocacy partners value having support to explore options and find solutions to the many varied issues they may be experiencing. I believe that providing people with the information they need to make decisions, allows people to feel more positive and in control of their situation.

As an advocate, you often work with people who have different outlooks on situations and my partnerships have certainly thrown up some challenges! What seems right for your partner may not be what they choose and you must support their decision fully. Self-reflection has been an invaluable skill that I’ve learned along the way and feeling able to access support and supervision from the project coordinator is crucial.

My most challenging advocacy role was due to a clear clash of personalities. I realised very soon into the partnership that we weren’t ‘gelling’ and I was fortunate to be able to discuss this openly with the project coordinator in order to ensure the partner was given an advocate that they could build a relationship with.

Most partnerships have given me a huge sense of satisfaction. It is such a buzz to work through someone’s difficulties and find a solution.

Advocacy is solution focussed but as a peer advocate there is a real skill in being able to identify areas of need and tease out the thoughts and views of the individual.
I have supported people with difficulties such as finding alternative housing and preventing people losing their homes, looking at care packages, liaising with professionals in many situations, practical help such as ensuring people’s end of life wishes are upheld, arranged help with domestic tasks such as cleaning and dog walking, made calls, chased up professionals and challenged services where necessary.

Advocates are unique in that they are able to spend time which other professionals simply don’t have. They build a relationship with partners and will support them in decisions that others may not agree with. This relationship of trust and mutual respect enables you to present alternatives in a way that is not ‘pushy’ or forceful. You are simply saying, ‘Have you thought about this?’ This enables an open route of communication. Most people are very receptive because you are not a figure of authority, you are standing at their side to provide strength and knowledge when needed.

I would like to think that I have made an impact on services where I have acted on behalf of a partner to raise issues and challenge decisions or practice.

I get a real buzz from getting a positive outcome for someone I am supporting. Being able to support those facing their cancer journey alone is so rewarding and being able to make things better at such a difficult time has given me a real sense of satisfaction. Cancer Advocacy is very varied, it’s challenging along with being highly rewarding.

Peer advocacy is not for everyone but if you have a personal experience of cancer and are a driven and pragmatic individual, then cancer advocacy may be for you.

I was allocated two advocacy partners within a reasonably short space of time, both were gentlemen. One was married and living at home with his wife, the other was divorced and living with one of his sons at his rented accommodation – which could only be a short-term situation.

The relationship with the first partner was not required for very long as his daughter was undertaking an advocacy role very ably and contact was mostly with his wife due to his increasing anxiety and dementia. Visits soon ceased and information was passed via phone calls. After a few further calls from myself to check if anything else was needed and, in agreement with Kath, it was then left that the couple would contact BJF again if and when they required advocacy support.

The second gentleman had quite a range of needs as he was homeless and his benefits and prescriptions needed to be sorted out and up-dated. These were addressed and following him living in other temporary accommodation (including unfortunately a garden shed), I helped him to successfully apply for a housing association bungalow in the area of his choice. Kath and I then also physically helped him to move in and we ensured that he had all of the basics such as bed linen, furniture, kettle, crockery and cutlery.

His life was and continued to be, quite chaotic due to his numerous medical conditions which included anxiety. This was exacerbated by a number of occasions when other agencies, such as the Department of Work and Pensions (DWP), really let him down and failed to provide a timely and supportive service.

This partnership continued for some time and, approximately twelve months later, I requested that he
be allocated another advocate due to my own developing family needs and caring responsibilities. This was also quite timely as I was beginning to feel that he came to regard me as a friend, which is a considerable compliment but wasn’t the role that I was there for.

Both this gentleman and one of his sons have given excellent feedback on the service that BJF has provided, his son actually saying a huge thank you to me adding that he did not think that his Dad would have come through it without that support.

I am currently still inactive as an advocate although have been attending most of the team meetings and on-going training. I do feel a little guilty about this however during this time I have been able to support both a relative and friend who are currently undergoing treatment for cancer. This is particularly due to the knowledge and understanding that I have gained whilst being associated with the project and I am delighted that my learning is still being utilised.

I have certainly learnt a lot – which will never leave me. I have a number of contacts and understand more fully where to go for further information.

Due to the on-going BJF training, I have kept abreast of benefit developments such as Personal Independence Payment (PIP) and Universal Credit. This certainly helped in supporting the second gentleman mentioned previously as well as my relative.

Finally, I have met a lovely, dedicated team of people at BJF who I know I could turn to for any further advice.
I had time on my hands. I had done volunteer work in the past so I started looking for volunteer opportunities. My friend put me on to Brighton & Hove Impetus. That’s how I found out about Macmillan Impetus Cancer Advocacy.

Many years ago I ran a small residential unit for drinkers. I had a client diagnosed with cancer who declined treatment. I contacted Macmillan and they sent round a nurse. She was really tenacious and she made his last months a lot more tolerable. I’ve had family members with cancer too. I’ve always thought of Macmillan as a highly reputable organisation.

Since I have been an advocate I have supported 2 clients. Both clients had specific goals. With the first client it became obvious that we really liked each other. When I met him he had completed treatment for cancer of the larynx and was recovering. He had lived without central heating for about 15 years but after getting ill he was feeling the cold and needed heating. I sent many emails and also spoke to the housing association to chase the heating installation. I supported the client by being present when he made a phone call to the electric company. I handed him the phone. He would not have done it himself. We got to where we wanted to in the end. He got the heating installed. We also discussed options of support available. He is now seeing a befriender.

During the time I was supporting him he also contracted skin cancer. He was fearful of losing the use of his hand because he’s a guitar player. I was able to accompany him to an appointment and was with him when he got the diagnosis. It was a privilege to know him.

My other client’s aim was to get a social care assessment. I thought it would take months as it seemed that social care assessments were not taking place. I liaised with the care manager and attended the social care assessment. She said she would be happy to work with the Macmillan Impetus Cancer Advocacy Service in the future. This partnership working has helped to raise awareness of the service.

Being a volunteer advocate means being able to help someone identify a goal that on their own they wouldn’t be able to achieve. To have that clearly defined goal helps to give you a direction and really helps to build the relationship with the client. When the client feels you are getting somewhere they tend to have a bit of faith in you.

It has taught me more patience. It makes me feel pretty good being an advocate. It’s very satisfying when you achieve what you set out to do.

Being a cancer champion adds another dimension. I particularly enjoy going to OPAAL and Macmillan’s National Cancer Champions Board. It is useful to hear about other services and their experiences.
I am 64 years old and I have retired. I worked for 22 years in Sandwell Social Services department. Prior to that I was a registered childminder looking after 3 children alongside my own 5 children. I gained qualifications in Advanced Care Management and NVQ4 in Care Management.

I really enjoyed my job but I wanted to spend quality time with my family. We moved out of the area for a while to start a new life in the country. Unfortunately family illnesses meant I was daily returning to the Midlands to care for my family members. My son in law, mother and sister all sadly passed away from cancer. I have seen the emotional impact it has on families. I still care for my parents and elderly neighbours, including my ex-mother in law.

Although I retired early at 55, I felt something was missing – I had a lot to give to people going through cancer, this drove me to volunteer. I saw the advert in the local paper and knew this was what I wanted to do.

As a Manager in a care setting I worked with many people, clients and staff and I have always found time to listen to people when they need it. My colleagues and friends say I am a bubbly person. I love life and spend lots of time with family and friends, especially going away with my husband in our caravan and travelling farther afield to new and exciting places.

I am a very active, hands on grandmother and I am committed to supporting my daughter and her children following the death of her husband. Although retired, I couldn’t possibly stop working. Being a cancer advocate gives me the best of both worlds, I get to support people but I don’t have the pressures of being a manager.

My first advocacy partnership didn’t really go very far. The lady I was supporting was struggling financially but I soon discovered she was receiving all the benefits she was entitled to and had already received a Macmillan grant. It was a struggle to find her any financial support she hadn’t already received and when we had exhausted all avenues my partner suggested we end the partnership. Whilst I couldn’t really do anything for her, I know I tried my best to help get all the support that was available.

I now have a new partnership with a couple in their fifties. The husband has cancer and his wife is having difficulty coming to terms with it. She herself has many of her own difficulties to overcome including arthritis and mental health issues. She is struggling physically to care for him and worries constantly about what the future holds for them both. With my knowledge of the care system I feel confident I can help them to get all the support they need.

They tell me they both look forward to my weekly visit. I have supported them with filling out benefits forms but most of all I am a listening ear and offer reassurance to them both.
I speak openly about advocacy and the Sandwell Cancer Older People and Advocacy (SCOPA) project to former colleagues who like myself have retired and would benefit from volunteering. I get so much back, it’s not so much about me as it’s a very rewarding role and I get as much back as I put in. It’s a two way street and it fills a small void in my life knowing I am helping someone who is going through a difficult journey.

This is our third Cancer, Older People and Advocacy (COPA) programme publication. This time we focus on the stories of the older people affected by cancer who are providing support for their peers. They are peer advocates or Cancer Champions or, in some cases, they are both.

Our heartfelt thanks go to the 19 older people affected by cancer who have freely shared their personal stories, allowing us an insight into why they volunteer and why, for them, independent advocacy is so important.

We once again extend our thanks to our Cancer, Older People and Advocacy (COPA) delivery partners. They have recruited, trained and supported the older people who tell their stories here.

We commit to making every effort to share all of these stories across a range of social media and web-based platforms so that every story gets an individual hearing. Our COPA programme blog has been extremely successful and our gratitude goes to the many volunteers who have contributed blog posts over the last few years as this undoubtedly contributed to our success in becoming a finalist in the UK Blog Awards 2017.

Our grateful thanks go to the following delivery partners’ volunteers who contributed to this publication:

• Sefton Pensioners’ Advocacy Centre (SPAC)
• Getting Heard (formerly Oxfordshire Advocacy)
• Independent Community Advocacy Network North (ICANN)
• Sandwell Advocacy
• Beth Johnson Foundation (Staffordshire & Wolverhampton Cancer Advocacy & Support Service)
• Dorset Advocacy/Help & Care (Dorset Macmillan Advocacy)
• Impetus (Brighton & Hove)
• Age UK Northumberland

Thank you to all of our peer advocacy volunteers across the COPA programme as well as to our local and national Cancer Champions for their continuing support. Without their support this important work could not take place.

We remain extremely grateful for the unwavering assistance provided by Macmillan Cancer Support both in funding and practical terms. We have been working with them now since 2011. Macmillan Cancer Support remain committed to extending our work and expanding our reach and we hope to work successfully together for many years to come. It continues to be a pleasure and our partnership is an example of how great things can be achieved when voluntary sector organisations work together, focussed on the benefits to those who use services.

“I get as much back as I put in.”
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.
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.