



# Giving a Voice

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Advocacy on behalf of people with dementia and people with cancer: a study of the effects on service users' lives

### The Beth Johnson Foundation (BJF)

The Beth Johnson Foundation (BJF) is a national charity dedicated to making 'a future for all ages'. We want everyone to enjoy a great later life, which means we as a society need to make changes at a strategic and practical level. Conducting cutting edge research, advising policy makers, and initiating pioneering age-friendly programmes, the Beth Johnson Foundation is at the forefront of making these changes happen.

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# Foreword

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This is a review, carried out by The University of Salford, of advocacy work undertaken over recent years by BJF. The work has been concentrated in two projects focused respectively on meeting the different needs of people with dementia and people with cancer.

Advocacy is a simple but important concept. It effectively helps to provide a voice for individuals whose needs may not be being met. This ranges from simply providing emotional support to people able in some measure to represent themselves, to more formally representing and 'advocating' on behalf of clients who are less able to articulate their own needs, to a range of agencies.

The advocate also helps people to navigate the systems that patients need to deal with, including those of the health, social services and benefits agencies. For anyone having to deal with such systems for the first time, the task can be daunting.

Advocacy also includes just being a 'friend' at a time of uncertainty for a person who is fearful and does not know what is going on, or what to do.

Providing practical support is an important element, and this includes obtaining background information and providing guidance on how things work and what the options are. This is important, not only for the patient but also for their relatives and friends, helping to de-mystify the issues, and to identify the best choices.

This report highlights some of the outcomes from BJF's advocacy work, and some lessons for the future. The topics explored are potentially relevant for all of us as we get older, as well as for our friends and relatives. The report also usefully helps raise awareness of the stereotypes and the ignorance that surround some health conditions.

Overall, the report finds that BJF's approach in both of the areas where we have delivered an advocacy support service – cancer and dementia – has had a very positive impact on people's lives.

Our job at BJF is now to let more people and institutions know about this approach, and the lessons we have learnt, encouraging others to adopt and develop the advocacy model across the UK.

**Colin Hann**

*Executive Chair, BJF*

# Executive Summary

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The Beth Johnson Foundation (BJF) is a national charity dedicated to making the UK age-friendly. Among their general activities are two advocacy projects – on behalf of people with, respectively, dementia and cancer.

These two projects work in distinct geographical areas (Stoke, Staffordshire and Wolverhampton in the case of cancer, and North Staffordshire and Stoke in the case of dementia). To enable the charity to develop a rigorous model and to obtain the resources that could be used to gain additional contracts in other geographical areas, there was a need for a full impact evaluation.

In January 2016 the University of Salford was invited to propose a plan to evaluate those two projects. The aim of the evaluation, which has been approved by BJF, and for which ethical approval was gained from the University of Salford (HSCR 15-165, 21 March 2016), was to assess the effects of these two projects on users' lives, in order to inform decisions about whether the services should be continued, or improved, and whether they should be extended to other geographical areas.

The two advocacy projects are significantly different in the kinds of conditions they are dealing with and the duration of their existence, and the services they provide reflect this. The dementia project is led by a project manager, aided by a project coordinator. The project facilitates an advocacy peer support group for people with mild to moderate dementia. No volunteers are involved in this project. The cancer project has a project manager and several area coordinators, and also works with trained peer volunteer advocates, who have personal experience of cancer and additional skills with which to support individuals.

## Methodology

Qualitative methods (individual interviews with project managers, and users of the cancer project; focus group discussions with members of the dementia project's peer support group, as well as with the coordinator and volunteers; and individual interviews with two relatives of individuals affected by severe dementia) were used to evaluate the following:

- Data collection, storage and analysis
- Recruitment and assessment mechanisms
- Interventions and activities

- Skills and training of volunteers
- Immediate outcomes for users
- Users' views on the service, and their satisfaction with it

## Key results and conclusions

Overall, the feedback received from the users of both of the services was very complimentary, particularly in respect of the people involved in providing the service. Participants in the evaluation reported getting valuable benefits which were reported as being essential in helping people to cope with the different illnesses and range of challenges they posed. Benefits ranged from helping people to sort out practical issues such as bills, adjustments to their homes and complex entitlement issues, to emotionally supporting them throughout the course of their illness, and providing a voice for them or their carers when needed. The service provided them with a 'safety net', or 'peace of mind', and with somebody they could talk to who understood and empathised with them. The advocacy element of the service has been greatly appreciated, particularly as participants were often faced with difficulties they were unable to cope with unaided. Findings from the study highlighted the success of advocates in achieving successful outcomes for their clients.

The degree of difference that participants reported the services as having made to their lives was remarkable, and expressed in comments such as:

If it wasn't for the advocate I would have topped myself.

If it was not for the Beth Johnson Foundation, I would not be around.

It stopped me going into a really black hole...

## Recommendations

Considering the findings of this evaluation, it is strongly recommended that these two projects should continue and, if possible, that the scope of their activities be expanded. It is strongly recommended that efforts should be made to obtain additional resources to promote and extend the current services to wider geographical areas.

Some more specific recommendations for improving the current service include:

- awareness raising to increase knowledge and understanding of dementia in people working in establishments that serve people with dementia, as well as in the general public
- some thoughts on finding out how to address clients' requirements for dementia expertise and services, with greater involvement of health professionals, particularly GP practices

- developing the capacity for greater involvement of carers of people affected by dementia
- exploring how the referral pattern for the dementia project could identify and attract more individuals in the earlier stages of dementia
- exploring how to attract and retain more volunteers in respect of the cancer project, and to consider whether to employ a paid volunteer coordinator
- exploring different ways of training volunteers for the cancer project – gathering current and past trainees' views about their experiences of training might yield a better understanding how to improve the training.

In summary, the data collected and analysed in this evaluation indicate a very good level of service, which was specialised in respect of the two conditions, with great satisfaction among the service users. Proposals indicating a need to improve the current provision were few and modest in scope.

# Introduction

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The Beth Johnson Foundation (BJF) is a national charity dedicated to making the UK age-friendly. Their mission statement states:

We want everyone to enjoy a great later life, which means we as a society need to make changes at a strategic and practical level. Conducting cutting-edge research, advising policy makers, and initiating pioneering age-friendly programmes, Beth Johnson Foundation is at the forefront of making those changes happen.

As a research leader in this area, a source of strategic advice for policy makers and a provider of practical services and training, the BJF gets involved in all parts of the change-making process. To enable the charity to be at the forefront of making the required changes, there was a need to adopt a unique model of operation.

Advocacy is an activity that aims to influence decisions within political, economic and social systems and institutions. Advocacy, in all its forms, seeks to ensure that people, particularly vulnerable people, have their voices heard on issues important to them; it is a process of supporting and enabling people to:

- express their views and concerns
- access information and services
- defend and promote their rights and responsibilities
- explore choices and options.

Under the Care Act 2014, local authorities must involve people in decisions made about them and their care and support, and must appoint an independent advocate in a particular set of circumstances. The aim of the specialist advocacy is to meet the duties placed upon local authorities under this Act and to make available non-statutory advocacy services for targeted groups. The experience and skills gathered at the BJF could be used to support local authorities in achieving this goal.

In particular, research has shown that people with dementia can be subject to discrimination and lack of consideration when decisions are made about them – often they are excluded from the decision-making process and deprived of the opportunity to have their voices heard (Wells, 2006). Dementia advocacy has been highlighted as an effective way of supporting older people whose cognitive capacity is subject to progressive deterioration and securing their right to play an active role in decision-making processes affecting their lives (Scourfield, 2007). There is much to learn about this form of advocacy and its effectiveness (Brown et al, 2013).

At present, access to independent advocacy on behalf of people with dementia is limited, and the Alzheimer's Society (2009) has called for increased access to such services. BJF is an advocacy pioneer, having initiated citizen advocacy in 1989 and advocacy on behalf of people with dementia in 1998 (BJF, 2012). The Foundation's dementia project provides advocacy support to hundreds of older people living in Staffordshire who are affected by dementia (McKenna, 2015).

Furthermore, with the growing number of older people living with cancer (Macmillan Cancer Support, 2015) there is a great need to provide them with support and information concerning a wide range of issues (for example, treatment and care, employment, social and financial difficulties, and so on). BJF's advocates aim to help these people to stand up for what they need and want and to safeguard their entitlements.

Against this background, BJF has identified advocacy as an appropriate intervention to support older people at the most vulnerable times in their lives. Currently two advocacy projects are delivered – for older people affected by dementia and older people affected by cancer. These two projects currently work in distinct geographical areas – the cancer project in Stoke, Staffordshire and Wolverhampton and the dementia project in North Staffordshire and Stoke. To enable the charity to develop a rigorous model and to obtain the resources that could be used to gain further contracts in other geographical areas, there was a need for a full impact evaluation.

In January 2016 the University of Salford was invited to propose a plan to evaluate these two projects. The aim of the evaluation, which has been approved by BJF, and for which ethical approval was gained from the University of Salford (HSCR 15-165, 21 March 2016) was to assess the effects of these two projects on users' lives, in order to inform decisions about whether the services should be continued or improved, and whether they should be extended to other geographical areas.

## Methodology

A mixture of qualitative methods – individual interviews with project managers and users of the cancer project; focus group discussions with members of the dementia project peer support group, the coordinator and volunteers; and individual interviews with two relatives of individuals affected by severe dementia – were used to evaluate the following:

- Data collection, storage and analysis
- Recruitment and assessment mechanisms
- Interventions and activities
- Skills and training of volunteers
- Immediate outcomes for users
- Users' views on the service, and their satisfaction with it

The two projects are significantly different, both in the kinds of conditions they are dealing with and in the duration of their existence, so the services they provide reflect this. That has affected the way these two projects have been evaluated.

The dementia project is led by a project manager, aided by a project coordinator. The project facilitates an advocacy peer support group for people with mild to moderate dementia. No volunteers are involved in this project. The evaluation of this service was therefore conducted by means of a focus group discussion with members of the peer support group, a personal interview with the project manager and telephone interviews with two carers of individuals with severe dementia.

The cancer project has a project manager and area coordinators and also works with trained peer volunteer advocates, who have personal experience of cancer and additional skills with which to support individuals. For the evaluation of this service the following methods were used:

- Telephone interviews with service users (n=9)
- A focus group with coordinator and volunteers
- An interview with the project manager

The data generated from these interviews was subjected to thematic analysis, to draw out the key themes presented in what follows.

## Conclusions

As previously mentioned, the two projects are significantly different in the nature of the illnesses they are dealing with, their history and the level of their resources. Evidence for the value of each project is therefore presented separately in the two main chapters describing the projects, with a summary of overall conclusions and recommendations at the end of the report.

# Advocacy on behalf of people with dementia

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## THE PROJECT

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### Overview

BJF is an advocacy pioneer, having initiated citizen (generic) advocacy in 1989, and dementia (specialist) advocacy in 1998. Two full-time members of staff, including the manager, deliver the project. The project is funded by two Clinical Commissioning Groups (Stoke and North Staffordshire).

The caseload at the time of the evaluation was fifty-nine, which was shared by the two members of staff. In addition, the project facilitates a peer support group, which consists of six people with mild to moderate dementia, who are helping in raising awareness of the illness locally and nationally. Since individuals with dementia have very specific and often very complex needs, no volunteers are involved in this project.

An evaluation of the dementia project carried out in 2001 identified that the average length of time spent with a client is four months and three weeks.

### Data collection and usage

Data is collected on a regular basis and quarterly and annual reports are produced and published.

### Recruitment and needs assessment

Most of the referrals are in respect of people who are in the advanced stage of their dementia, and mainly made by a third party:

So the referrals come from a third party, i.e. social worker, health practitioner, family member, care manager...

— *Staff*

As the referral is predominantly from a third party, a careful assessment of the client's wishes needs to be undertaken. It is often difficult to ascertain their needs, given that the

family members and carers often have a clearer voice than the person with dementia, a circumstance that needs to be handled carefully:

...as, in many instances, the client's wishes differ greatly from the referrer's. For example, the family might refer because the Mum is in care home that they don't like and in actual fact they don't like the care because it is too expensive and it's eating into their inheritance. So we have to be very aware of the agenda.

— *Staff*

...and family conflict is a big issue ...it is about inheritance, so social workers will refer

— *Staff*

The assessment focuses on establishing client needs.

Establishing what they would want may be difficult to determine due to the advanced stage of their dementia. We are issue-based dementia advocates so referral comes with an issue, but there are always underlying issues to the issue referred.

— *Staff*

The projects get involved in lots of safeguarding issues, but mainly those concerning finance:

Safeguarding is predominantly finance based. It represents 90 per cent of our referrals relating to safeguarding.

— *Staff*

Members of the dementia project support group who have generally mild or moderate dementia have usually found out about the service through other organisations, such as Revival, Approach Café, memory clinic, GP, and others.

Members of this group who we have previously supported with an issue are unusual for the project because we are normally referred clients at an advanced stage of their dementia. Members of the group are at an early or ... mid stage of their dementia and they offer each other peer advocacy, and they are brilliant.

— *Staff*

## Interventions and activities

Since the project is independent and neither resource nor organisation led, the main feature of the service is a person-centred approach. The main operational elements of this service are aimed at spending time with clients and giving them a voice:

I was with a man ... and they (health care professionals) were saying he was quite advanced in his dementia, and I happened to know him; he had been re-referred and he just could not get his words out. And I sat with him, saying, 'How are you?', and it took him minutes but then he was saying 'Not so clever'. It was giving him *the time*.

— *Staff*

A client has a review, and you attend the review, and you are sitting there, and I'll say 'Oh, where is Mr A?'. And they'll say, 'Oh we are not bringing him in because it is quicker to do it without him,' So I'll say, 'Oh no, it is his review, so bring him in.' So, it is just making sure their rights are adhered to, and it is *giving them a voice actually*.

– *Staff*

Another part of the service provision involves supporting clients in defending and safeguarding their rights. The evaluation asked members of the dementia project peer support group how the group and the advocate supported them

We talk about what sort of help we might need; for example, about power of attorney, the need to contact a solicitor, things like that.

– *User*

They gave me loads of information, but having an advocate at the dementia peer advocacy support group meetings helped me to understand.

– *User*

Participants in the support group reported getting involved with other different organisations, where their voices on issues that are important to them can be heard:

I have become involved in different action groups locally, relating to dementia – with different agencies.

– *User*

Another group of clients comprises the relatives and carers of people with severe dementia. Since these individuals are unable to deal with their own issues, their relatives contact the service for help and support. And the service provided help and support to relatives, particularly in respect of understanding what services were available, and how to manage the complexity of these, including legal processes:

When [the advocate] got involved, we had social services and the stay at home team, and that meant that, rather than going straight for the stay at home package, they sent in the stay at home team, the town council ... that was absolutely fantastic.'

– *User*

Furthermore, when asked how they would describe the service to a friend or a neighbour, this carer said:

I would describe it as something they needed to have if they were going to have to go through a legal process, as I did, because they would be better informed and they would have people sat with them that could act in their best interests. And we don't know what their best interest is, because we don't know what services are available and we don't know what the guidelines are for elderly people.

– *Carer*

Another relative of the carer's mother, who was in an inappropriate home, managed to find a better arrangement with the assistance of the project:

That would never have happened, never happened without [the advocate].

– *User*

It is the terminology that is used [by the advocate] to establish a level of care that particular person is going to need.

– *User*

Members of the team really understand them and express empathy:

She was as therapeutic to me as she was for my Mum.

– *User*

## Immediate outcomes for users

Since individuals with advanced dementia are a highly vulnerable group of people, no volunteers are involved in this project. There had been volunteers previously, however. Evaluations had highlighted that ‘having dementia volunteer advocates doesn’t work because it’s so specialised...and too complex’ – *Staff*. Therefore, only the views of the peer support group members were collected during a focus group discussion, and telephone interviews with two relatives and carers were conducted.

## Making a difference

It is difficult to quantify somebody’s wellbeing, especially in the case of people diagnosed with dementia. However, there have been some responses from the clients that indicate that the service has made a difference:

Say they give you a smile when they normally wouldn’t give you a smile, and that happens frequently ... then you know you’ve made a difference.

– *Staff*

When someone you have been visiting, and you’ve got to know, and they wouldn’t have talked and sat ... with their back to you, and then suddenly they are talking to you ...that makes a difference.

– *Staff*

...when you know they have been given the choice of a better care home.

– *Staff*

[The advocate] has gradually helped me to understand that they are not the problem, I am not the problem, it’s the illness that’s the problem.

– *User*

Participation in the dementia project peer support group helped the participants to feel more active and gain a better outlook on life:

...has kept me more active.

– *User*

Doing things, it's made me see that you can live a comparatively good life having the diagnosis.

— *User*

Relatives and carers reported having personally benefited from being in contact with the service from the support the service offered, through having someone outside the family to talk to, and also from knowing that their family member with dementia had someone to share things with:

... really eased my conscience ...

— *Carer*

So [The advocate] flagged up that security issue [her mother letting people into the house who she didn't know]...and she got involved with the care package and flagged some things up that I would never have thought about' — *Carer*

She was my Mother's voice [in meetings].

— *Carer*

She was like a sounding board.

— *Carer*

...and she genuinely was her [client's] safety net.

— *Carer*

They were fantastic, absolutely fantastic. I found that my Mum told [the advocate] things that she wouldn't tell me.

— *Carer*

A further example shows how an interaction with the service boosted a relative's confidence and supported her in becoming a 'public speaker':

I have told [the advocate], if there is any way I can help ... I was asked to stand up and give a few minutes talk on how advocacy helped my mother ... I told [the advocate] I'm not very good, but she said it is literally just a few minutes, and I did, and I met so many nice people and interesting people. I faced my demons and managed to stand up and talk.

— *Carer*

This empowerment enabled the same carer to stand up for her rights on a different occasion:

I actually felt brave enough to say, well you're not just moving her anywhere, you've done it before and this time I want to choose.

— *Carer*

In addition, users reported that BJF has helped to raise awareness and reduce stigma in respect of dementia:

I've talked to loads of people that didn't know anything about this and I think that we, because we are suffering ourselves can actually express it better, tell them how we feel on a day-to-day basis, and make them understand better, and this platform was provided at BJE.  
— *User*

## Improving interaction between the clients and support services

With the knowledge and experience obtained by the team during the last two decades, it can significantly support a more accurate assessment for these individuals.

I will give you an example. We worked with a lady with dementia and we asked, 'Do you go shopping?' And she says, 'Yes I do my own shopping.' What they don't say is that she goes with her daughter, and she sits in the car and the daughter does her shopping, and I have been there.  
— *Staff*

Clients felt it was better to attend clinical appointment together with a member of the team:

I felt that I've needed her to come with me to the memory clinic, and she has been there and supported me ... I can talk to her more than the new guy I am going to see at the memory clinic.  
— *User*

## Peer support

Regular meetings of the dementia project peer support group enabled the participants to support each other, to feel that they are not alone in this ordeal and to come to terms with their illness:

By having these meetings, it's getting you to understand your problem.  
— *User*

It is a good thing ... by talking about your problem you might have a solution.  
— *User*

Members of the dementia project peer support group reported having developed very close relationships with the other participants:

Friendship we have built up ...  
— *User*

I feel a part of a family.  
— *User*

I have got friends for life.

– *User*

It's a joy because they are at the mid-stage of their dementia and they offer each other peer advocacy, and they are brilliant.

– *Staff*

## Users' satisfaction

Participants in the dementia project peer support group were *overwhelmingly* pleased with the services provided by the project:

If it was not for the Beth Johnson Foundation I would not be around.

– *User*

It stopped me going into a really black hole.

– *User*

Without [member of staff] I would not have contact with ...

– *User*

If it weren't for them we wouldn't be talking. I wouldn't be, anyway.

– *User*

## Ideas for improvement

Participants were asked for their views on ways in which the service can be improved. Information about that was gathered from both the users of the service and from its providers.

### *Users' views*

As mentioned above, the majority of users expressed extremely positive feedback about the service provided by the project. During the focus group discussion they came up with some ideas for potential improvements:

- Many participants were aware of the financial constraints but raised the need for more meetings. The benefit of the meetings is extremely valuable, so they expressed their wishes to have more of them.
- Very often people affected by dementia experience inappropriate responses from the general public, as a result of lack of awareness of the nature of this illness. BJF staff were highlighted as being instrumental in creating better public understanding, for example, by going to the supermarket, or into a nursing home, to raise awareness of the symptoms at different stages of dementia. However, there is scope for further awareness-raising with the general public, which BJF could inform and play a role in.

- The most significant point raised was about the involvement (or lack of involvement) of GP's surgeries and health professionals. Users highlighted challenges when dealing with health professionals, particularly when different health professionals were treating them on different visits (for example, different GPs, or different staff at the memory clinic). Therefore, users recommended that there should be greater consistency in which health professional the patients see, and a greater level of 'dementia expertise' integrated into different health services, particularly in GP surgeries. This could potentially be provided by BJF.

## Recommendations from Staff

Members of staff interviewed put forward a few suggestions:

- Currently BJF gets involved with people affected by dementia relatively late, often as the last resort. This limits the benefit that the staff can bring to these clients. Staff reported that, if they could be involved from the early stages, 'the benefit would be immense', and in many cases that could save people going into hospital.
- Another area for improvement is to expand the participation to include carers as well. 'We don't work with carers but carers do benefit.'
- The current team is very small, and there is a need to have more coordinators.

Since recruiting volunteers is not currently possible, there is a need for further funding to enable more coordinators to be employed, which could improve the current service and to extend it to other geographical areas.

### CASE STUDY 1

It was through Mum's social worker. I had never heard of Beth Johnson. I didn't know what they did and I didn't know they provided such a service. The advocate contacted me and said could she come and see me with Mum, and chat, and then, after that, she would visit Mum on her own, but she would always let me know when she was going to visit Mum and report to me afterwards – after she had visited.

Mum passed away at the end of last year (2016). And the advocate contacted me and sent a card, and she said some lovely things about my Mum and actually I am still in touch with her.

The advocate showed such empathy and such understanding of Mum's situation, she'd obviously dealt with people with dementia for a long time and had a wealth of knowledge in that area, and I just felt we were on the same page from the outset. I mean, we had Mum at home on her own for five years without any involvement from social services, till it got so bad that she was phoning the police and saying that there were people in the house and all that sort of thing. And that's when social services got involved. So I had got a lot to talk to the advocate about. There was all her history and all the little things that had happened, and how me and my husband were the sole

carers of my Mum, and although we lived thirteen miles away, we were there every day, or we had Mum here every day.

Even when Mum went into a care home, as the social worker said, 'I can't be responsible for her anymore', she visited Mum at the home, Mum had a nasty fall in the home, down some stairs, and the advocate visited Mum when I wasn't there and talked to Mum, and she told me she was going to visit the manager of the care home, and genuinely she was her safety net really, and she was fantastic.

She was like a sounding board, and I could talk to her about anything, anything at all. And while I didn't see her very often, it was just that peace of mind: that I had got somebody there who was on the same page as me and knew what I was talking about, basically. Because I felt, rightly or wrongly – and my husband, as we are joint carers for her – social services and the staff, whilst they were very good and very professional, they never understood. She [the advocate] was as therapeutic for me as she was for my Mum.

They sent in the stay at home team, the town council did, and that meant that she had four people coming in four times a day and staying for an hour at a time for two weeks, and that was absolutely fantastic, and I didn't know what to expect. And the advocate said, 'I am glad it is going well but the time for you to really examine what is going on is when the care package itself is put in place.' So, for instance, when the carers' stay at home team step down and an agency comes forward, and perhaps sends somebody in for, say, three times a day for twenty minutes... and that's when the problems started, because somebody would come in and do a sandwich for Mum, and they'd say, 'There's your tea, there it is,' and then we'd go three hours later and the sandwich was still there, so either Mum couldn't see it or she had forgotten it was there. And the advocate also said she was passing – 'and your Mum let me in and it concerns me that she let me in as she had forgotten she had met her before, I showed her my ID but she couldn't see as she was blind.' And she explained she'd been before, but the advocate said, 'It does concern me that she just lets me in'. By this she flagged up that security issue, because you just don't know who is about. So it was a security angle, and she got involved with the care package and flagged some things up there that I would never have thought about.

I have told the advocate, if there's any way I can help, to let me know and last year I spoke at a conference at the Medical Institute at Hartshill. The advocate said, would I just stand up and give a few minutes' talk on how advocacy helped Mum. I told her about my public speaking, I'm not very good, but she said, 'Honestly it is literally just a few minutes.' And I did, and I met so many nice people, and interesting people afterwards. I said to her, 'If you do another one, I'll do it again.'. I faced my demons and managed to stand up and talk.

## CASE STUDY 2

I was in church on a Sunday morning, and our vicar had said prayers for my Mother because my Mother has Alzheimer's, and she is about in the later stages. She is extremely poorly and she had had a bad fall, and she had been hospitalised, so they said prayers in church and a lady came up to me and said, 'I hope your mum is well,' because she knows her, as she used to be part of the congregation many years ago, and she said, 'This isn't a very nice time for you.' And I said, 'No, and I'm looking for a new home for her now, and I am very unsettled.' And she said, 'Has your Mum got any support?' And I did say to her, 'I don't think my Mum would benefit from any support, as she is not able to communicate anymore, and I'm not sure exactly how that would work.' But she said, 'They could represent your Mum at meetings.' This lady had herself had assistance from the Beth Johnson Foundation, and she gave me their number. So the following day I rang.

Well, firstly I wasn't really quite sure what to expect, to be honest, or how it was going to work. My mother was, at that particular time, in a home that was not necessarily suitable for someone with the type of Alzheimer's she had, and the particular stage that she was at. And so I genuinely felt quite alienated by the people at the home, the people that ran it, the people that owned it, and other residents, as she [her Mum] had become unpopular because she was noisy. So I wasn't quite sure how it was going to work, and I didn't really want to share personal information with a complete stranger, but I ended up finding out, though, that that's exactly what I did. When she [the advocate] said, 'Now is there any way in which we can help you?', I said, 'You can stop them from being unkind, first of all, first off.' And then the advocate was amazing. She went to the home, she spoke to the manager, and she also spoke to other staff at the home. She visited my Mother every week because she said to me, 'I do think they are being particularly unkind. They are putting her out of the way of the others, because your Mum is noisy. There are lots of difficulties here, I can see. She probably isn't best placed there, and I don't think they are acting in her best interest.' Fortunately, the district nurse that was visiting at the time met with the advocate on one occasion when she was in there, so the advocate shared her concerns with her, and she [the district nurse] said to the advocate that she had exactly the same concerns, and she was recommending that a checklist was done for the Decision Support Tool (DST), to see whether my Mum's case would actually trigger a DST. So she did it, and she was quite high on the checklist, and from that a DST was done, and they started to look for a new home. That would never have happened without the advocate's intervention.

But the advocate was amazing to me, I've got to say there were many times I have sat in a hallway, very anxious about going into a meeting, but she has accompanied me to no less than four DST meetings and a DOLs meeting, all where we were sitting front of a panel of people. Whereas you are unsure, perhaps elderly yourself, because there's a lot of elderly people I've met who still have relatives in their nineties and they are fighting their corner. It's a very difficult road to tread and you do need someone to guide you. I can't speak highly enough of them, I can't. If the advocate has been on holiday, there was always been someone else there to tell me exactly what's happening, and say 'I will make the phone calls for you.' And until the advocate comes

back off holiday, there have been meetings cancelled until she comes back and until she is available because she has the overview.

The advocate never knew my Mum outside of her Alzheimer's but she has taken the time to get to know what she was like. She wanted to know what things she used to do, and where she would go and what her interests were like, what she looked like. She provides the family with a dignifying process.

As a team, the BJJ help to save people's sanity. And I genuinely mean that because, as I said, it is a terrible process to lose a parent to Alzheimers. It is the long goodbye, because they are not the person they used to be and the Beth Johnson service, for me, has helped me to remember who my Mum was.

# Advocacy on behalf of people with cancer

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## THE PROJECT

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### Overview

The service has been established since 2014. Following an 18-month pilot in Stoke on Trent and North Staffordshire, the service has been expanded to cover all of North, Central, South, and East Staffordshire as well as the City of Wolverhampton.

The project is funded by Macmillan Cancer Support, managed by a project manager and overseen by a steering committee. The steering committee consists of members mainly from BJC, Macmillan Cancer Support and OPAAL.

Five volunteer coordinators (one in each area) have been recruited to engage and train peer volunteers to act as advocates for people diagnosed with cancer and their carers. The peer volunteers are supported by regular meetings with the volunteer co-ordinators, and through on-going training opportunities. The majority of volunteer coordinators found out about the service by word of mouth in the first instance, which they followed up by searching for the service on the internet, with one volunteer stating that she found out about the service directly from searching the internet (without prior knowledge of BJC).

From the start of the service, a total of 400 users have been referred to the service. Of those, 306 (77 per cent) are patients and the rest are carers. Since the pilot was conducted in North Staffordshire, the majority of the referrals have originated from this area.

### Data collection and usage

Data is collected on a regular basis and quarterly reports are produced and published. The data collection has been developed and refined over the life of the project. For example, in the beginning, no information on the stage of the disease at the point of recruitment was collected. However, after a few months:

Macmillan said it would be interesting to know [the stage of the disease], so we do collect that information now: whether people are newly diagnosed, going through treatment, post treatment ...

— *Staff*

All the information is collected and stored on a database called 'system for advocacy management' (SAM). This is a national database, which is for the use of advocates and volunteers, and is administered by OPAAL. The statistics form the basis of quarterly reports to the steering committee

This information mainly feeds the quarterly reports for my steering committee and quarterly reports for the national project management group.

– *Staff*

## Recruitment and needs assessment of users

The majority of referrals come from Macmillan Cancer Information Centres, which are based in the hospitals and other Macmillan projects. Another significant source is self-referrals. People who have picked up the service's leaflet, or have heard of the service and contacted it directly.

There are clear criteria for accepting new users:

We are very clear that there should be issues that people are having ... there has to be a diagnosis of cancer and they should be over 50.'

– *Staff*

Since this is a relatively new service, the team have adopted a proactive approach in their recruitment process:

We've spent time going to any event, going to talk to groups, cancer-specific support groups, older people groups, as well as going to the cancer services professionals groups ... all the Macmillan projects ... and other organisations, so we spent a lot of time and energy.

– *Staff*

This proactive approach has been resulted in better outcomes:

We have just come to the end of the second year and we had, I think, 350 referrals in the first two years and then in February and March, the first two months of the third year, we have had 57 referrals, so they are coming in now, and obviously that is good.

– *Staff*

At the time of the June 2016 Quarterly Report, the majority of the clients recruited were at their treatment stage (39 percent). However, information on around 30 percent of the users was missing reflecting the fact that, as previously mentioned, this information was not collected from the start of the project. That indicates the development that has occurred in the collection and collation of information.

## The role of the volunteer coordinators

As has been mentioned, most of the volunteers found information about the project on the internet, after being signposted to it by word of mouth. The volunteers reported that they

were drawn to the role because they were interested in doing some form of volunteering and supporting people living with cancer. They reported that the opportunity was:

...up my street.  
 – *Volunteer coordinator*

or that:

I wanted to give something back ... to support people who were living with cancer.  
 – *Volunteer coordinator.*

Volunteer coordinators are expected to fulfil three different roles – as advocates, coordinators of volunteers, and promoters of the project.

As an advocate, we are here to promote independence, to be a voice, to be an information point and a listening ear. As a coordinator of volunteers it's to be supportive, available and to be approachable, and also to try a recruit volunteers. And then, also, we are to be promoters of the project. We will go out to give talks ...to networking events ... to gain more volunteers and more referrals.  
 – *Volunteer coordinator*

Identifying suitable volunteers was reported as not being a straightforward process. Since the role of the volunteers is significantly unique, it creates some difficulties. Volunteers need the right skill set, and the requirements, particularly the responsibility, of being this type of volunteer does not always suit everyone who applies for the role.

A lot of people have applied to be volunteers and probably initially have not fully understood the role of an advocate and responsibilities that gives. Then they've undergone the two days' induction training, and then decided it is not what they want.  
 – *Volunteer coordinator*

They'd wanted more of a friendship, befriending, supporting type of role, ...rather than the level of an advocate which comes with a certain amount of responsibility.  
 – *Volunteer coordinator*

Actually, out of a number of volunteers who have been trained, only a very small number have actually come through the training to be suitable volunteers, to be able to move forward, ensuring their health and well-being in the process of carrying out the role.  
 – *Volunteer coordinator.*

An additional barrier for a successful recruitment of volunteers is the requirement for flexibility:

They wanted set days that they can volunteer on, and this isn't a role where you can do that; you have to be quite flexible. So I think that put a lot of people off.  
 – *Volunteer coordinator*

## Interventions and activities

The main feature of the service is comprehensive support. This entails not only advocacy, but a support role as well. Anybody with a cancer diagnosis, who is over 50 years old, and has any issues can be supported by the service in an effort to resolve the issues that confront them:

So, it's been a whole range of issues, from ... finance, ... general information, housing, we have had several homeless people, ... transport ... bills...

– *Staff*

The service is involved in partnership working with various organisations:

We work in partnership with other Macmillan projects in the area, information centres, the benefits advice, and Disability Solutions, ... local hospices.

– *Staff*

In order to promote the service, several joint activities with other organisations are taking place:

... jointly doing road shows, a pop-up road show to older people in retirement villages ... an event for Dying Matters during Dying Matters week, which brought together a whole range of groups and voluntary and statutory organisations.

– *Staff*

Another activity developed by the service is the Cancer Champion Group. Cancer Champions are ordinary members of the community who are prepared to undertake some training, following which their role is simply to raise awareness with their family, friends, neighbours, and others.

The Group is made up of volunteers (older people), clients of the service and carers, as well as some 'professionals'. Members of the group regularly get Newsletters. Furthermore, they are consulted on issues concerning organisational changes, and they have taken part in the various evaluations of the service.

## Immediate outcomes for users

Users reported a tremendous number of important benefits that they have gained from the service.

### *Practical benefits*

Individuals who have been in touch with the service have reported a range of practical benefits. Advocates helped them:

- To get apparatus to make their life easier:

I think it was through them ... I have had a chair lift for the bath... and they are trying to get me a wet room.

– *User*

■ With their finances, utility bills and housing:

They have also got us a bit of money to help with different things ... a bit of carer's allowance.

— User

She [the advocate] took a lot of stress off me because I've had a lot of trouble with my electric company, and she dealt with all that and sorted that out for me.

— User

■ With attending appointments or meetings:

She [the advocate] has been to the hospital appointment with me.

— User

I had to go to a few meetings at work ... related to my absence ... I was really sick and felt anxious ... helpless...scared. She [the advocate] said she would come with me and if I needed her to, talk for me.

— User

■ By referring them to other services:

... like they also referred me to psychology and I think I would have been waiting for that but they saw me right away.

— User

### *Emotional benefits*

The Advocates and trained volunteers were reported to have helped people affected by cancer by helping them to live independently and providing them with appropriate emotional support. Extremely positive feedback has been received by the users who have been interviewed:

...someone always there to talk to...can ring up at any time.

— User

...made me less frightened.

— User

...someone to speak for me and someone on my side.

— User

I feel like I have a friend... someone I can depend on.

— User

### *Users' satisfaction*

As with those who are involved in the dementia project, participants in the cancer project were overwhelmingly pleased with the services it provided:

If it wasn't for [advocate], I would have topped myself.

— *User*

Brilliant, fantastic. If you needed an angel you've got one. Can't speak too highly.

— *User*

... a very good service to have, and they take a lot of stress and worry off me.

— *User*

## Ideas for improvement

Participants were asked for their views on ways in which the service could be improved. Information about that was gathered from both the users of the service and its providers.

### *Users' views*

As has been reported above, users of the service were extremely pleased with the care they had received, and the majority had no ideas about how to improve further such a good service. Their only comments were about the need to develop more robust and efficient advertisement of the project, and to enable the service to cover other regions.

Since this project includes volunteer advocates, their views have been gathered as well, mainly on the training process. It was suggested that a lengthy period of time for the training might be beneficial:

The training was OK, it gave an introduction but within the time and the resources that are available .... It is very difficult to actually prepare somebody fully for an advocate role.

— *Volunteer coordinator*

In order to assist in the smooth process of new volunteers into the role of advocates, participants saw a need for:

...some kind of signpost handbook for newcomers, for volunteers to be able to reference.

— *Volunteer coordinator*

...just a highlighted view of who you could contact with regard to certain issues...Like a directory.

— *Volunteer coordinator*

### *Staff views*

The main issue raised by the staff who had been interviewed was the need to change the original model of work to a new and more effective one. The original model, which was suggested by the national project group, was based on large numbers of volunteers, who were to be trained to be peer volunteer advocates in every area. The current economic climate, on top of the difficulties in recruiting and training volunteers (as mentioned above), has resulted in a very small group of volunteers, and there is a high turnover.

Changing the model to include a dedicated paid volunteer coordinator could enable the current provision to be expanded and enhanced. The post-holder could be responsible for recruiting, training and supporting volunteer advocates, and looking at volunteering options within the Project, thereby enhancing the volunteering experience. Having paid area coordinators and advocates will ensure the consistency of a higher quality advocacy service:

# 4 Conclusions

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Overall, the feedback received from the users of both of the services was very complimentary of the service, particularly in respect of the people involved in providing the service. Participants in the evaluation reported getting valuable benefits from the service, which were reported as being essential in helping people to cope with the different illnesses and range of challenges they posed. Benefits ranged from helping them with sorting out the practical issues such as bills, adjustments to their homes and complex entitlement issues, to emotionally supporting them throughout the course of their illness, and acting as a voice for them or their carers when needed. The service provided them with a 'safety net', or 'peace of mind', and with somebody they could talk to who understood and empathised with them. The advocacy element of the service has been greatly appreciated, particularly as participants were often faced with difficulties that they were unable to cope with unaided. Findings from the study highlighted the advocates' success in achieving desired outcomes for their clients.

The level of the difference that participants reported the services as having made to their lives was remarkable. Participants used expressions such as, '... if it wasn't for the advocate, I would have topped myself'; 'If it was not for the Beth Johnson Foundation, I would not be around' and, 'It stopped me going into a really black hole.'

Considering the findings of this evaluation, it is strongly recommended that these two projects should carry on and, if possible, expand their activities. In this regard, it is strongly recommended that efforts are made to obtain additional resources to promote and extend the current services to a wider geographical area.

Some more specific recommendations for improving the current service include:

- awareness-raising to increase knowledge and understanding of dementia in people working in establishments that serve people with dementia, as well as in the general public
- some thoughts on finding out how to address clients' requirements for dementia expertise and services, with greater involvement of health professionals, particularly GP practices
- developing the capacity for greater involvement of carers of people affected by dementia
- exploring how the referral pattern for the dementia project could identify and attract more individuals in the earlier stages of dementia
- exploring ways of obtaining resources that would enable the cancer project to change its model, with the recruitment of more paid staff

- exploring how to attract and retain more volunteers in respect of the cancer project, and to consider whether to employ a paid volunteer coordinator
- exploring different ways of training volunteers for the cancer project – gathering current and past trainees’ views about their experiences of training might yield in a better understanding how to improve the training.

In summary, the data collected and analysed in this evaluation indicate a very good level of service, which was specialised in respect of the two conditions, with great satisfaction among the service users. Proposals indicating a need to improve the current provision were few and modest in scope.

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