

‘Compassionate Advocacy: How advocacy helps older people affected by cancer’

Compassionate Care Conference 12 February 2015

Macmillan 2011
“Walking into the unknown”

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CANCER SUPPORT**

Inequalities in cancer care

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Initially commissioned to:

Produce national advocacy framework for older people affected by cancer

Devise “Power Questions” (used in Macmillan’s revised & expanded Cancer and Older People booklet)

Train Macmillan helpline staff to understand benefits of advocacy

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dorset
advocacy

Pilot Project





Successful application for pilot to Big Lottery's Silver Dreams Programme

Joint funded by Macmillan

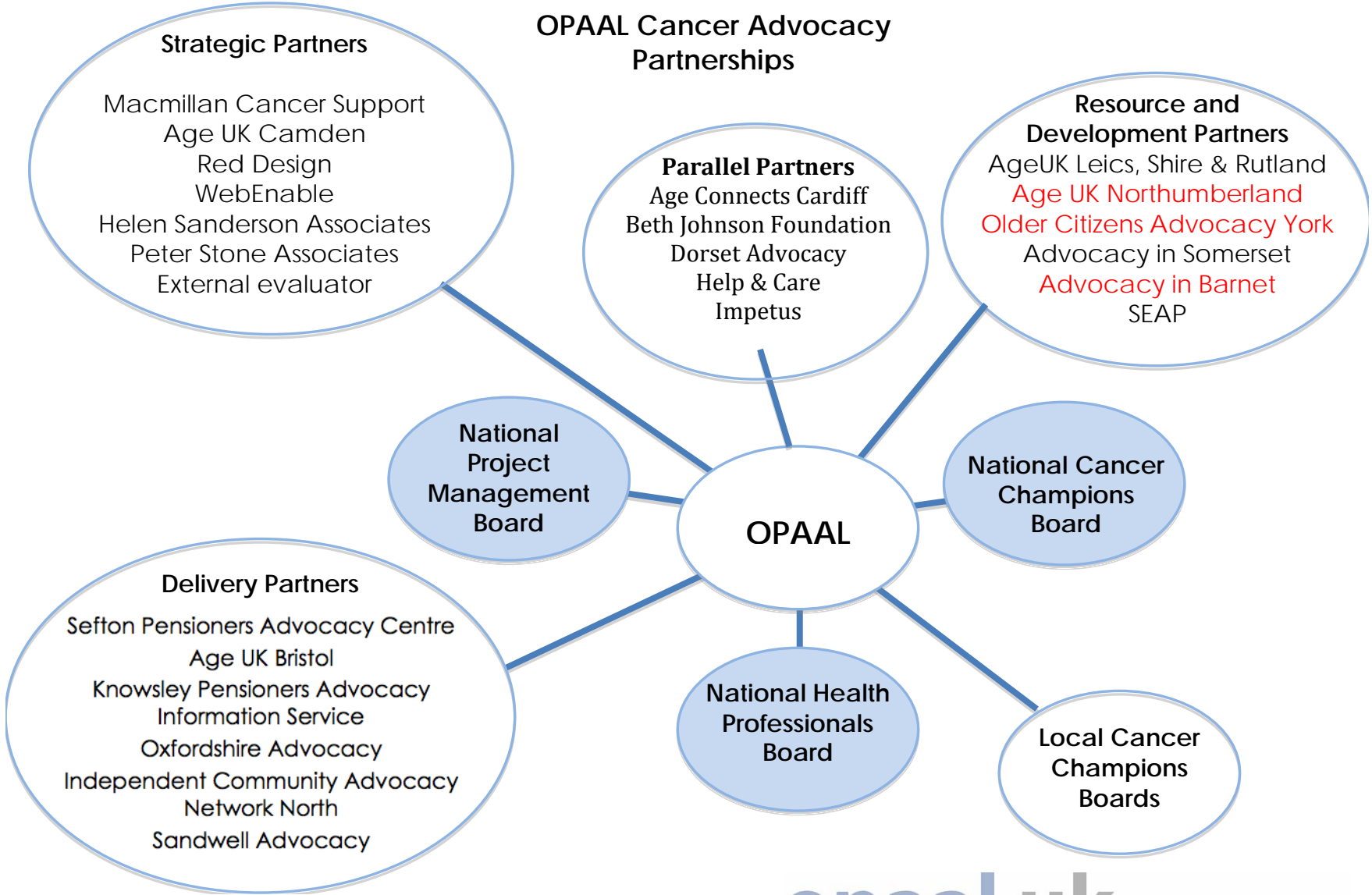
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Then £1M BIG Lottery award
+ Macmillan funding (national/regional)



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OPAAL Cancer Advocacy Partnerships



What we do

- Recruit, train and support older people affected by cancer to become peer advocates
- Provide peer advocacy support for older people affected by cancer
- Recruit Local and National Cancer Champions to design and manage services for their peers



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With Macmillan's support we've:

- Published stories of older people affected by cancer and their Peer Advocates on our blog
- Published 'Every Step of the Way': 13 stories of older people affected by cancer and their Peer Advocates
- Developed the first Macmillan national helpline advocacy referral process



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Brian's story



“My cancer diagnosis has been life changing. I was diagnosed in the March and I thought, ‘This is my last summer’. You wake up every day thinking about it.”

“My advocate Bob is easy to chat to, he is very easy going. We met up at my home and have also been out for coffee. Bob found out about the local Myeloma Support Group and went along with me to one of their meetings. I am now in regular contact with them and attend their meetings when I can.”

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“He found out about the local shop-mobility scooters and went with me to try them out. I still need support to do my shopping but it makes it much easier. Bob can help to remind me who is involved in my care I’ve seen so many people that I don’t always know who’s who.”



Bob is meticulously well organised and at the same time very caring. He calls and asks ‘What disasters have you had this week?’ and I say ‘I’ve been windproof this week!’

Bob has been supporting Brian for 7 months. To date, there have been 23 visits, 2 meetings & over 30 telephone calls

Mary's story

They found that I had a tumour on my kidney and said that they needed to take it out right away. I was in a right state, but it all happened so quickly that I went along with it in a daze. I think I thought that I was glad that they had found the problem and that I would soon be cured. It was after the operation that more bad news came. I was told that further tests showed that I had lung cancer as well. This news absolutely devastated me and I went to pieces for a while.

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I was introduced to Christine. She was to be my advocate. She told me that she had had breast cancer. That made me think that I was talking to someone who understood how I may be feeling and that would understand the procedures that may be happening to me over the next few weeks and months. Christine started telephoning me from the moment we met. At first the calls were just to check how I was but, then she started to visit and helped me write some letters. She has started to help me sort out my money problems. Christine also came with me to the Doctors and that was very helpful. Perhaps the most helpful thing so far was she has visited the consultant with me.



Mary's case is still open. Over two months there have been 2 visits, 1 meeting and 3 telephone calls made

Ron's story

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

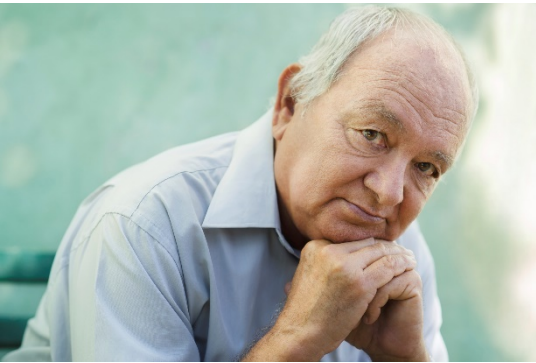
When the letter came, it said I should take somebody with me. The problem is that I didn't know anyone well enough to ask them to go with me. I should have realised that I was going to get some bad news by the fact that they did suggest I didn't go alone.

*Anyway, I did go alone and yet despite the clues, I was really shocked that I was told that I had prostate cancer. I was frozen and
unable to do anything.*

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



David was a really good listener and I was to tell him my story very easily and without difficulties. He had had an operation for cancer himself. I look forward to David coming around or telephoning me. I know

he will be there when I need to go to the consultant again, which is coming soon, when he tells me what is going to happen. I will not have to go to another appointment alone.

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What our peer volunteers say

- *“I was struck by just how many people out there are alone”*
- *“It’s always interesting, sometimes challenging, always rewarding, work with lovely people, never pressured, always supported.”*
- *“I enjoy making a big difference to my advocacy partners, they tell me I do this and I can see a real change in them.”*



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OLDER PEOPLE LIVING WITH CANCER

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Peer advocates supporting older people affected by cancer



October 18, 2012
by [kathparson](#)
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Silver Dreams/Macmillan Project: Cancer, older people and advocacy

We are very happy to be working on an exciting, innovative partnership project supporting older people affected by cancer. My name is Kath Parson I am the Chief Executive of the Older People's Advocacy Alliance, otherwise known as OPAAL.

OPAAL led a partnership of six advocacy provider organisations to develop the framework that with the support of the Silver Dreams Fund and Macmillan is now being piloted in Dorset through Dorset Advocacy and Help & Care Bournemouth; AgeUK Gateshead; The Beth Johnson Foundation Stoke on Trent and Sefton Pensioners' Advocacy Centre.

Advocacy is all about Voice, Choice and Control and this project is about putting that into practice. Older patients and carers are being trained as independent peer

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Related developments

- Older People's Cancer Voices: Department of Health funded
 - Filmed stories & best practice guide – working with commissioners of older people's cancer services
- Sanofi Patient Group Bursary Scheme:
 - Training older people affected by cancer to present films to commissioners and health professionals





The future?

- Older people's cancer advocacy services continue to increase across the UK
- The vision is that this service should be available to every older person affected by cancer
- There are around 1.3 million people aged 65 or above living with cancer in the UK

CONTACT

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