



Easing the cancer journey

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Having to travel long distances or stay away from home while being treated for cancer takes its toll in anxiety, stress and isolation. Could more be done to ensure policies that centralise services don't make some patients' lives unbearable?



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A life saver. Without this charity-run bus, driven by a volunteer who is himself a survivor, many cancer patients living in the north west of Ireland would have to make the long journey to Galway and back by public transport – a round trip of up to 600km. Some of these passengers get to stay at the Inis Aoibhinn facility, attached to the cancer centre

Since his diagnosis in 2009, Dearn McClintock has been undergoing tests and treatment for prostate cancer at a hospital 250 km from his home.

“I realise that centralisation and medical economies require cancer patients to travel to large centres for highly skilled procedures,” says Dearn, who lives in Donegal, Ireland. “But for the patient travelling long distances for treatment it’s grim stuff.”

Just how grim, and just how much travelling long distances for cancer treatment affects quality of life, treatment decisions and even outcome, might not be fully appreciated by policy

makers and funders of cancer services.

According to Richard Flaherty, of Cancer Care West in Ireland, it is all too easy to underestimate the effects of travel. “Around 40% of people who have been through cancer say it has affected them psychologically,” he says. “Put yourself in the shoes of someone of who is 70, lives in a rural area, is coming to the city for the first time, and finds themselves in a long line for treatment in a busy hospital. They have to find accommodation if they’re receiving a course of radiotherapy. They’re experiencing the stigma and fear of cancer, often away from their family. They’ll be feeling

tired, and maybe sick, and maybe they’ll have to spend five days a week for two months staying in a Bed & Breakfast on their own.”

For some, the solution is a new kind of cancer facility: accommodation centres specifically created – normally by voluntary bodies – to support patients who live a long way from their cancer centre. One of them is the Cancer Care West Lodge in Galway, Ireland. Named Inis Aoibhinn, it provides a place to stay for patients undergoing radiotherapy treatment at University Hospital Galway – recently designated one of Ireland’s eight national cancer centres. And it provided Dearn McClintock with a lifeline.

Dearn lives a good four hours away from the Galway hospital travelling by car; there are no trains and the roads are not fast. “It’s quite a journey even when you’re on good form,” he says. “I thought it was grim when I had to travel after biopsies, until my wife drove me home when I had a catheter. I remember every bump of that road.”

Most of the time, Dearn drove himself to hospital and back. When he started a seven-week radiotherapy course in September last year, his best option was to drive down to Galway on Monday morning, stay in a Bed & Breakfast (B&B) for the five days of treatment, then drive home on Friday.

“By the second week it was getting hard,” says Dearn, who is 54. “I was quite sick from the radiotherapy, and it wasn’t great being stuck in that B&B room 22 hours a day. I was homesick and feeling quite lethargic, and really didn’t have the energy to get out. By the time I got home at the weekends I was totally drained.”

Then he was offered a place at Inis Aoibhinn for the remainder of his treatment – a room with its own

Patients with metastatic colorectal cancer received fewer systemic regimens if they lived far from a cancer centre

bathroom, the company of other people going through similar experiences, and 24-hour nursing support to help him with increasing treatment side-effects. “Spending time with other patients with prostate cancer made a lot of difference: there was a feeling that we were comrades in arms.” He is all too aware that many others travelling to national centres in Ireland for treatment are not so lucky.

Impact on treatment outcomes

There is currently a dearth of research on the impact of travel on cancer patients. A literature review published in the *European Journal of Cancer Care* in December 2000 commented on the paucity of valid research to draw on. But there are some studies which take patient experiences like Dearn’s beyond the anecdotal. An American study in the journal *Cancer Causes and Control* in August 2006 showed that women with early breast cancer were less likely to choose optimal treatment including breast conservation surgery and radiotherapy if they lived a long way from the treatment facility.

A Canadian study, published in *Oncology Exchange* in August 2011, indicated that patients with metastatic colorectal cancer received fewer systemic regimens and were less likely to enter a clinical trial if they lived a long distance from a cancer centre.

The Oxford Cancer Intelligence Network in the UK has also provided some evidence that the travel distance may be a crucial influence on treatment decisions. In its report on travel times to radiotherapy centres for head

and neck cancer patients in England between 2006 and 2008, it concluded that, for patients requiring courses of radiotherapy longer than six weeks, “travel times may be a discouraging factor when considering the choice of radiotherapy over surgery”. It noted that providers have been looking at ways of minimising the impact of travel times on patients, such as organising hostel/hotel accommodation near to the radiotherapy centre.

Renée Otter, former director of the Northern Comprehensive Cancer Centre in Groningen, the Netherlands, has made the case for keeping services more local when cancer services are being reorganised – partly because of quality of life issues for patients (see Cross Talk, *Cancer World* March–April 2013). She points out that more than 65% of cancer patients in Europe are aged over 60 when diagnosed, and many have mobility problems. For the 30%–45% of patients in Europe who are diagnosed when their cancer is too advanced to be curable, being able to spend as much time as possible at home, or at least with family, becomes even more important.

A good place to stay

Facilities that try to address some of these issues are springing up across Europe in towns and cities whose cancer centres serve large and often rural regions.



At home in CLAN Haven. Avoiding the stress of long daily journeys or the loneliness of a hospital ward or Bed & Breakfast makes all the difference to patients and families

In Aberdeen, Scotland, the CLAN Haven accommodation centre offers patients and their relatives and carers a home from home for up to seven weeks while they attend Aberdeen Royal Infirmary for treatment. Relatives can also stay there while the patient is in hospital. It accommodates radiotherapy patients for up to seven weeks in 27 bedrooms with their own bathrooms. The infirmary serves the whole of the North East of Scotland and the islands of Orkney and Shetland.

It was set up by the charity Cancer Link Aberdeen and North (CLAN)



11 years ago. “Aberdeen is the oil capital of Europe and accommodation is in short supply and is also very expensive,” says Debbie Thomson, CLAN chief executive. “Options for radiotherapy patients travelling any distance were limited – hospital bed, hotel or B&B, or if they were lucky a relative living close to the hospital.”

The health authority, NHS Grampian, refers radiotherapy patients to the centre and pays for their stay, although the centre receives no statutory funding and is reliant on donations and fundraising. There

are kitchen and lounge areas, support personnel, and a range of support services on offer – complementary therapies, relaxation sessions, counselling, social events and even a minibus to ferry patients to hospital and back.

“Without us, people would be very isolated – maybe in a hospital ward,” says Debbie Thomson. “Some would have shattering daily trips. Cancer is stressful enough, and you don’t want the additional burden of travel. We have thousands of letters from people saying how their stay with us made their situation bearable. I think it’s the peace and the freedom to do

what they want that people appreciate most.”

Al Richards, 77, lives on the island of Orkney, and eight years ago was prescribed radiotherapy for prostate cancer at the Aberdeen Royal Infirmary. He knew he would have to fly down for treatment, but otherwise had no idea how he would manage. “I know some people from the island regularly flew down for treatment, but that was completely impractical.”

When a place at CLAN Haven was offered, “it was as if the sun had come out again, and everything became a little easier”. This year, Al has had to return to CLAN Haven to receive further treatment and a course of hyperbaric oxygen therapy at the hospital. His wife Margaret has been able to stay with him throughout the five-week course – without any need to return to Orkney.

“When you’ve got cancer, having your mind put at ease is extremely important, and I’ve spoken to many people with cancer who feel the same,” he says. “I know many people who come from Orkney for treatment, and they haven’t been off the island before and they feel very scared – not just because of the cancer, but about how they are going to manage, and what their family are going to do.”

“It can be quite hard travelling by air, and then it can be confusing getting around in the town, especially for older people who haven’t been here before. Travelling can also be very costly, and when you get to our age, you have to watch your outgoings.”

It’s a similar story for patients in



CLAN CANCER SUPPORT

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other European cancer centres that serve dispersed and rural populations. In Norway, the Varde Centre in Tromsø supports patients attending the university hospital, and is one of four national support centres for patients having to travel long distances. Opened in 2012 and run by the Norwegian Cancer Society in partnership with health authorities, it is a meeting place for patients and their families, providing a relaxation room, kitchen, information, support, activities and toys for children.

Centre co-ordinator Hilde Nordhus says that patients who have to travel long distances for treatment – sometimes many hundreds of kilometres – have an additional challenge. “Many have to be away from their families for many weeks. Those who have radiation treatment over several weeks miss their families and feel lonely and anxious. They say it is good to have the Varde Centre, where they can meet others in the same situation and facing similar challenges.”

Centralisation of cancer services, she says, is making the need for such centres more urgent. “I think that more cancer treatments should be given in rural areas, so that patients can be with their families and avoid travelling so far.”

The problems associated with travel to treatment are by no means

limited to areas of very dispersed populations, or only to adults. The impact of travel on the whole family becomes especially apparent in child cancer.

A policy issue

In 2010, the UK charity CLIC Sargent for Children with Cancer published the findings of an analysis of 10,000 records from its database of children who the charity has supported. It found that, while the development of specialist treatment centres has undoubtedly improved survival rates for children, travel to and from treatment centres can create significant challenges for young cancer patients and their families.

It found that 77% of childhood cancer patients do not live in a city with a principal treatment centre and that the average round trip travelled for treatment by children and their families is 60 miles, taking on average one hour 50 minutes. But some children and their families reported a round-trip of 902 miles, taking 16 hours.

CLIC Sargent for Children with Cancer concluded that this travel greatly increased pressure on families, causing “massive disruption to their work and family lives and their ability as a family to lead a ‘normal life’”.

Most cancer patients undergoing treatment know that ‘normality’ is an idea that changes substantially after

diagnosis. But sometimes it is the little, indefinable things which researchers and policy makers find hard to measure that make life bearable in the face of stress, exhaustion and separation: Dearn McClintock remembers that a conversation with a nurse at Inis Aoibhinn helped him overcome the diarrhoea that was making any form of journey virtually impossible.

What value do you put on such support? Many of the centres that provide it receive no state funding and are dependent on voluntary contributions – even though it is state policies driving the centralisation process that makes them so indispensable for patients.

Dearn McClintock wonders whether this is right. “I understand centralisation and the need for economies of scale,” he says. “But these centres rely on charitable donations and I think perhaps governments should be providing support.”

“You can only admire what organisations like Cancer Care West do to raise voluntary contributions to run such services. Inis Aoibhinn is the most positive place to be. The guests are cheerful because the staff are marvellous and it is all provided free of charge.”

“My strongest emotion experienced over the last three years has been gratitude to those that cared for me and my admiration for their skill and kindness to those of us in need.” ■

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