



# Mind the gap!

## *Who cares for patients after treatment is over?*

Specialists feel responsible for their patients, but lack time to offer long-term care. Patients feel abandoned as their treatment ends, but lack resources to seek the care they need. GPs lack confidence to deal with cancer-related issues, and feel it is not their job. **Simon Crompton** asks how health systems can overcome these barriers to get cancer patients the long-term care they need to get their lives back.

**T**he treatment is over, the cancer cured or controlled. What happens next? One, five, ten years later? For many people with cancer, 'next' is the hardest bit.

"It was this feeling that, 'I ought to be better by now,' says Kathy from the East Midlands in the UK, who finished treatment for colorectal cancer two years ago. "I've struggled lately with depression. I felt oddly guilty. It sounds bizarre, but I finally put on all the weight that I'd lost when I was ill after surgery, and everybody's saying, 'You look well, it must be so nice to be back to normal,' and it's very hard to actually say, 'No, I feel awful.'"

One reason Kathy felt awful was there was little incontinence care after she came out of hospital, and she experienced regular diarrhoea problems. "I went to see the GP, who said, 'I don't know what's going on and I can't really treat you with anything

because I don't know what the hospital are doing.' It made a big hit on my quality of life because I was always scared about going out.

"There needed to be somebody who offered the support as a routine, because you're not in a very good place to go and think, 'I need some help here and I'm going to go and find out how to access it and get it myself.'"

What Kathy needed after cancer was structures recognising that treatment for a severe life-threatening illness isn't an event, but a beginning. The support needs to go on. Yet the long term has been all too rarely in the sights of cancer clinicians, researchers and funders.

There are hundreds of thousands of Kathys across Europe. Around half of those with cancer live for at least 10 years after diagnosis, and there's evidence that one in three are still struggling with physical well-

being two years after discharge, and one in four have poor health over the long term. Research by the Nuffield Trust has shown that, 15 months after diagnosis, people with cancer are 60% more likely to attend accident and emergency units than the general population.

This isn't just the result of cancer, but its treatments. The late effects of treating the more common cancers, such as impotence and urinary and bowel incontinence in prostate cancer, are well documented. But there are countless others for virtually every cancer – physical, psychological, long-term, under-researched, but becoming alarmingly plain as evidence grows.

A 2016 study in the *Journal of Clinical Oncology*, for example, showed that people with multiple myeloma, non-Hodgkin lymphoma and cancers of the breast, kidney, lung/bronchus and ovary are up to 70% more likely



to develop cardiovascular disease as a result of their treatment than someone who has not been diagnosed with cancer (*JCO* 2016, 34:1122–30).

The reality of cancer long-term, then, can be a dark and mysterious place. Cancer patients making their journey into it all too often have to carry the physical and psychological burdens without support. Research from the University of Pennsylvania Abramson Cancer Center, published in 2016, found that two out of three women (65%) who had been treated for breast cancer and considered disease-free for at least three years had an unmet need for help with side effects (*Cancer Res* 2017, 77(4 Suppl):Abstract # P5-13-12).

The irony is that, while cancer is increasingly becoming a chronic disease, media and professional attention, and research and care resources, continue to coalesce around the dra-

matic ‘cure’ phase of cancer – the one-off interventions that save lives, not the measures that make the long-haul of life worth living.

As the American surgeon and author Atul Gawande recently wrote in the *New Yorker*, we may have too heroic an expectation of how medicine works. Chronic illness is commonplace and treatments have complications that require attention. “We have been poorly prepared to deal with it,” he wrote. “Much of what ails us requires a more patient kind of skill.”

### The ‘survivorship’ agenda

Is the tide beginning to turn? Living with and after cancer has now become commonly known as “survivorship” – a term that doesn’t go down well with all cancer patients. Some feel it implies

a triumph that many don’t feel, and has the same judgemental quality as “victim” and “victor”. Nevertheless, survivorship is now high on the research agenda in some countries.

### “Much of what ails us requires a more patient kind of skill”

In the UK, moves to improve understanding of what surviving means have been led by the charity Macmillan Cancer Support, which funds the University of Southampton’s Macmillan Survivorship Research Group. This year Macmillan produced a report powerfully documenting the experience of many people like Kathy (above) after cancer treatment (*Am I meant to be okay now?* Macmillan Cancer Support, October 2017).

## Systems & Services

“There is still much to do to support those who are struggling in silence or not getting the support they need,” says Claire Foster, who heads the research group. “We need to make sure we are supporting those with complex needs and those who are less likely to engage with more self-directed follow-up.

“But I think we are now learning much more about quality of life after cancer treatment and recognising that many people continue to need support to manage consequences of treatment in the years beyond treatment. Important research is going on.”

Foster’s own research has already uncovered interesting findings about those who may need most support. For example, depression and confidence in managing illness-related problems before treatment were found to be key predictors of quality of life two years after surgery for colorectal cancer.

### People who have had cancer fall down a crack between secondary and primary care

There are now Europe-wide survivorship initiatives to try to build understanding about what is experienced by cancer patients after treatment. The European Organisation for Research and Treatment of Cancer (EORTC) is developing an infrastructure to optimise long-term follow up among patients treated in clinical trials and promote data sharing. The aim is to foster scientific collaboration on long-term outcome research (see ‘Gathering long-term data on what happens next’, *Cancer World* Spring 2018).

And survivorship and rehabilitation was a main work package of the EU-funded Comprehensive Cancer Control Joint Action (CanCon), which ran between 2014 and 2016. This resulted in a series of recommendations for EU countries, including personalised follow-up care plans for every person emerging from cancer treatment, and more research to provide data on late effects and the cost-effectiveness of supportive care. These are to be followed up by the European Commission’s newly announced Innovative Partnership Action against Cancer.

But if Europe seems finally convinced of the importance of knowing more about long-term needs, the main challenge remains: creating services and structures that actually mean something to people who are struggling in a myriad of ways after they are supposed to be ‘better’.

### Redesigning services and structures

Who takes responsibility for the welfare of survivors? All too often, patient accounts suggest, people who have had cancer fall down a crack between secondary and primary care. Though health systems vary across Europe, the problem seem similar: specialist care loses interest or contact after treatment is deemed successful; general practitioners feel ill-equipped to address related issues arising; and the patient ends up feeling in no-man’s land.

As CanCon pointed out in its final report, lack of coordination between secondary and primary care, lack of funding, and limited capacity mean that in most countries effective long-term support remains an aspiration rather than a reality.

“There’s a recognition that second-

ary care just can’t cope any more with the increasing numbers of cancer survivors – incidence is increasing, survival is better, people have comorbidities,” says Eila Watson, Professor in Supportive Care at Oxford Brookes University and Chair of the British Psychosocial Oncology Society.

Various new models are being tested. Some are led by secondary care, using phone, postal or ‘self-triggering’ follow up, which allows people to get back into the hospital system after discharge if they have a symptom or worry. But many countries, such as the Netherlands, Denmark and the UK, are transferring more responsibility to primary care. To some extent, this is a response to pressures on secondary care, but it also makes sense that general practice is better adapted to providing the kind of personal, ‘incremental’ care that Atul Gawande believes is at the heart of good medical systems.

“We definitely need systems to provide ongoing support to those who need it, and primary care is often suggested as the place where this could happen,” says Eila Watson. “But at the moment, primary care does not have a structured formalised role in terms of follow-up after the diagnosis and primary treatment are over.” She says she currently knows of nowhere in Europe where this is the case.

Why is this? Why is ongoing support in primary care such a problem to organise? Lack of resources, lack of professional confidence and lack of coordinated support planning seem to be significant barriers.

### Netherlands: primary care/ specialist agreed care plans?

Henk van Weert, Professor of General Medical Practice at the University of Amsterdam, believes GPs are quite



capable of providing support to people who have been treated for cancer and should lead support planning. Yet his research is indicating that many GPs are reluctant to carry out follow-up care of cancer patients because they don't feel capable of dealing with many cancer-related issues – and also aren't being paid for it.

“In the Netherlands, GPs keep on seeing cancer patients, but not on a scheduled scheme,” he says “They might give support to patients as normal patients, but it will be unstructured. Most GPs I know tell me that they won't start off talking to them about cancer: they say they think the patient won't like it.”

Van Weert says there is no evidence that continuing to receive specialist care long after treatment is over benefits the patient. If patients feel worried about their GP's lack of specialist knowledge, the key is to reassure them that there is quick and easy access back to secondary care. In the Netherlands, it is possible to get a patient to a specialist

the next day, says van Weert. “We need to end the misunderstanding that if they start going to their GP, hospital specialists won't welcome them anymore.”

He wants to see support care plans agreed between primary and secondary care. But the picture is complicated by the fact that the required support needs vary so much from cancer to cancer and patient to patient. “In colorectal cancer, for example, you'll need a fairly uniform protocolised care plan, which is quite safe in the hands of a GP. In breast cancer, defining the GP role may be more difficult because there are so many different types, and lots of the therapies that go on for years.”

### Denmark: redefining responsibility for follow-up

In Denmark, the government has encouraged a greater role for primary care in long-term survivor support. But following a major review exam-

ining which cancers might be best suited for GP support, it became clear that cancer specialists were often reluctant to give up control. Bolette Friderichsen, a Danish GP and Board member of the Danish College of General Practitioners, says that many hospital doctors have been reluctant to lose contact with patients because of ongoing research and fear of losing out financially.

“In turn, I'm aware that many of my GP colleagues are reluctant to take up this task because they are not oncologists, and are worried about missing late effects or recurrence. We are not trained in this.”

“But the important point is that we already have these patients in our waiting rooms in general practice. They have very reasonable expectations about what their family doctor should be able to provide. So whether or not we want this task, it is on our table. We might as well lift it.”

She is all too aware that former cancer patients don't know where to go for help, or simply don't go any-

### Drug research failing on late effects

- Only in the past 20 years have trials of cancer treatment started to evaluate the effect of treatment on long-term quality of life, as well as classical outcomes such as survival.
- A systematic evaluation of oncology drug approvals by the European Medicines Agency (EMA) in 2009–13, published in the *British Medical Journal* last year, found that most drugs entered the market without evidence of benefit on quality of life.
- A recent analysis in the *American Economic Review* concluded that pharmaceutical company investment is distorted away from studying the long-term effects of treatments.
- This year Dutch epidemiologists reported in the *British Medical Journal* that industry-funded post-marketing studies do little to improve understanding of long-term adverse effects.

where. “I hear many of my patients say, when they come out of secondary care, that they feel like a piece of meat. They say: ‘I’m very grateful for the quick and competent treatment, but I saw a different person every time I went to hospital, they didn’t tell me what I need to know, and I was confused. What went on? Where am I now? Am I cured?’ It’s almost as if they have symptoms of post-traumatic stress disorder.”

It is the GP’s role, she says, to be able to address this. “The comprehensive and continuous care gives us some possibilities that oncological specialists do not always have,” says Friderichsen. “Of course, my patient needs to be assured that we can get help from other specialists when there is a problem. But little by little I want my patients to know that I am another kind of specialist than a hospital specialist. I am a specialist in my patients.

“At a hospital appointment, when you see a different person every time, does a woman who has had breast cancer get the chance to talk about issues to do with sex – for example, if her husband feels awkward about touching her new breast? In hospital,

will they be able to spot depression coming on, or give people the opportunity to talk about feeling guilty that they are sad even though they have survived?”

### World’s first GP guidelines

The Danish College of General Practitioners has just completed what are believed to be the world’s first guidelines for cancer follow up in general practice. Work on this has been led by Friderichsen. The aim is to give GPs more confidence in dealing with cancer. The first part addresses the need for family doc-

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tors to keep in contact with people being treated for cancer, and gives guidelines on touching base with the patient after active treatment has ended, addressing any psychosocial issues, and agreeing a personalised support plan that also takes into account the comorbidity issues. The second part is more biomedical, providing a basic oncological knowledge base with details about adverse and late effects, and guidance on early palliative treatment.

The devil of the detail, predictably, relates to how this is coordinated with secondary care. Like Henk van Weert, Friderichsen believes it is crucial that patients know they can be referred back to secondary care almost instantly if there is a hint of recurrence.

Under Danish cancer packages, former patients can get back to the hospitals and specialists that treated them before. But the responsibility of coordinating the whole of a patient’s cancer journey is still fraught with difficulty.

“There are so many different models of organising services, even in a small country like Denmark,” says Friderichsen. “There’s a political aim of having one ‘patient-responsible’ doctor you always refer to in a hospital. We suggest that the family doctor works in partnership with the patient-responsible doctor in the hospital, but we have some doubts about how well the patient-responsible doctor scheme will work, because they have so many other priorities.”

What if long-term supportive care were given a national priority, so that across the country structures that overarched primary and secondary care ensured that the wide-ranging physical and psychosocial needs were met?

### France: extending multidisciplinary to primary care

That is the model being aimed for in France, where survivorship care has been a focus of the National Cancer Plan, launched in 2009. According to Claudia Ferrari, head of the Care Pathways Department at the Institut National du Cancer, and one of the authors of the CanCon recommendations, finding ways to effectively coordinate survivorship care plans between primary and secondary care is key.

“We’re very aware of this,” says Ferrari. “Our systems are very hospital-centred at the moment. The difficulty is to link hospitals and primary care, because they function with a different logic. Hospitals are more inclined to retain what they have done, because they have their own resources, instead of sharing it with primary care.”

But gradually, and step by step, things are moving forward as the national cancer plan drives the concept of survivor care plans – and crucially, according to Ferrari, allows resources to be mobilised.

New multidisciplinary platforms that include nurses, social workers, psychologists, nutritionists and other health professionals are now being established outside hospital structures to support people when they leave secondary care. A trained co-ordinator – most likely a nurse – will coordinate between primary and secondary care, ensuring there is sufficient oncology input if necessary. “We know that this kind of coordination works at hospital level, but we still have to work on coordination with the primary care professionals,” says Ferrari.

To address this, the Institut National du Cancer is leading the development of a new national guide to support patients and the profes-

sionals involved in their care, as they leave secondary care, along with a framework for minimal standards in follow-up care plans. The guide will alert people to the issues that may arise after treatment, explain the need for a follow-up plan, set out healthy lifestyle issues, and provide access to patient organisations and networks of support.

Ferrari stresses that France does not yet have all the answers. But she knows that multidisciplinary teams and good co-ordination are absolutely fundamental. “We don’t want patients to fall in the gaps of a very complicated system. If we are not able to create something which is simultaneously simple and effective, no one will put it into practice. So it’s step by step, by hospitals and GPs in parallel.”

### UK: Finding a national solution

In England, as in France, the key to progress – even if slow – seems to be making what happens ‘after cancer’ a national policy priority. The National Cancer Survivorship Initiative was launched by the Department of Health and Macmillan Cancer Support in 2010, and researched best practice, piloted ideas, and developed recommendations which gave rise to Macmillan’s Living With and Beyond Cancer Programme. This aims to improve local cancer services, with planned and tailored support for every person leaving treatment.

Various arrangements are being piloted across the UK but, as Eila Watson points out, there will not necessarily be one single national solution. “I think there’s definitely a general move away from consultant-led follow-up, but I don’t know if you ever get one universal way forward,”

she says. “You need some sort of core underpinning principles about the best way to organise services, while also recognising that you need flexibility to suit local health service set-ups. I think that nurses, whether clinical specialists or primary care practice nurses, are likely to have a key role in most arrangements.”

## The key to progress seems to be making what happens ‘after cancer’ a national policy priority

The irony is that, given the universal shortage of health resources, making long-term support personal, incremental and local requires the coarse population-based strokes of national policy. And even then, progress is too slow for many people to notice. The cracks remain, and as the personal testimony provided by the new Macmillan report testifies, sometimes it seems there will never be a way out.

“I had to find all the help myself, whether that was trying to get referrals for cognitive therapy or meditation, it was just me that was doing it,” said Frances, from Leeds, who finished treatment for Hodgkin lymphoma four years ago, and found that physical problems continued, and anxiety problems were just beginning. “When I look back on that initial year, the support definitely dropped off a cliff, and the effects are lasting.”

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