

It's not just about surviving, it's about getting your life back

→ Peter McIntyre

Recent issues of *Cancer World* have looked at the physical and psychosocial damage than can be inflicted by radiotherapy, chemotherapy and surgical cancer treatments. The final part of our series on *Living with the consequences* looks at the transition from patient to survivor and the sort of tailored support survivors need to help them live their lives as fully as possible.

The International Agency for Research on Cancer estimates that around 20 million Europeans alive today have had a cancer diagnosis – more than 8.3 million of them within the past five years. This number is set to rise significantly as cancer survival rates and general life expectancy increase.

Cancer treatment has become a priority in many European countries, while the campaign against tobacco and for improved diet has raised the profile of prevention policies.

Now the need for better rehabilitation and long-term support for cancer survivors is forcing its way onto the agenda, as the long-term effects of living with cancer are better understood and as patient support groups become better organised. This complex area covers a huge range of needs, a long time scale and requires an interdisciplinary approach within and outside the healthcare system.

Many cancer patients make a good recovery and return to a fulfilling life. But millions more could live like them if support services were more available and better joined up. There is a clear need for more comprehensive rehabilitation and long-term support.

Each survivor has different needs. Some require short-term rehabilitation to recover strength and function. Others suffer long-term fatigue, heart problems, lymphoedema, incontinence, loss of sexual function or infertility. The problems may result from the effects of the disease or the treatment. Sometimes they do not become apparent for many years after the treatment has ended – particularly in the case of cardiac damage or new cancers arising from radiotherapy. The worry of what might happen in the future can be an additional burden for cancer survivors.

At this most vulnerable of times many survivors lose their jobs – despite anti-discrimination legislation. Loss of self-esteem, social isolation and loss of income can contribute to a cycle of physical, emotional and psychological decline with a substantial impact on quality of life.

According to a report by the US Institute of Medicine, up to 30% of women treated for breast cancer experience episodes of persistent psychological distress that interfere with their ability to cope with cancer treatment. At worst, feelings of depression, anxiety, panic and isolation can become disabling. Following treatment, women's concerns include fear

of recurrence, physical symptoms of fatigue or pain, changed body image, sexual dysfunction, persistent anxiety and fear of death, relationship problems and feelings of vulnerability.

The Institute recommends that each cancer patient receive a 'survivorship care plan' which should summarise all the information they need for their long-term care, and also include legal rights affecting employment and insurance, and the availability of psychological and support services.

WHAT SHOULD REHABILITATION INCLUDE?

Rehabilitation should focus on the needs of patients. For most patients this will include physical exercise to regain strength, movement and confidence, and psychosocial support. There is increasing evidence that physical and emotional confidence feed off each other.

The Department of Health Education and Promotion at Maastricht University and the Limburg Comprehensive Cancer Centre in the Netherlands have spent a decade trialling a combination of physical and psychosocial support. Groups of 12–16 cancer patients visited the rehabilitation centre for twice weekly physical training and for psycho-education aimed at enhancing quality of life.

As measured by physical, emotional and social function, quality of life improved significantly, with lower rates of fatigue by the end of the 12-week course, and the researchers concluded that "a rehabilitation programme for a mixed group of cancer patients is both beneficial and feasible," (*Eur J Cancer Prev* 15:541–547)

The trial is continuing to define the best interventions and timing. But already the programme is running in 60 centres in the Netherlands and in some parts of Belgium.



Fit for life. These patients are taking part in a rehabilitation programme at one of the centres that took part in the follow-up trial of the Maastricht study. They had completed their primary medical treatment at least three months previously but had been experiencing physical and/or psychosocial problems before the programme began

THE LANGUAGE OF SURVIVAL

The term 'cancer survivor' can mean different things to different people. The US National Cancer Institute suggests the following definition: "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life."

Cancer survivors may have many years of life ahead of them but can face physical, psychosocial and financial problems, which can be hard to deal with alone.

Rehabilitation has been defined as a process that assists the cancer survivors to obtain maximal physical, social, psychological and vocational functioning within the limits created by the disease and its resulting treatment*.

* Robert Kaplan, *Cancer and Rehabilitation*,
<http://www.emedicine.com/PMR/topic226.htm>

Concerns include fatigue or pain, sexual dysfunction,
persistent anxiety and relationship problems



Embarrassed no longer. Treatment for a head and neck cancer left this patient isolated and suicidal because he could neither eat nor speak properly. His life was transformed by a novel bone replacement that was grown in the patient's right-side latimus dorsi muscle and transplanted into his jaw. The right-hand image shows a CT scan taken after the transplantation

Irene Korstjens, from the Department of Health Education and Promotion at Maastricht University, says that physical confidence in patients boosts psychological confidence: "As their physical condition improves their social and psychological functioning improves too. Because they can do more, they get more self-assured and a feeling of control. Rehabilitation enhances self-confidence and autonomy. I think that is the way it works. Performing within a group stimulates people. They dare more."

Today, what began as a research project is becoming part of routine care in some centres and some health insurance companies are already paying for the programme. "The main issue now is to get the programme better known," she said.

In a sense, however, rehabilitation starts with treatments that minimise risk of side-effects, late effects, damage and mutilation. Less invasive surgery, lower doses of radiotherapy better targeted on the tumour, and targeted drugs which do less systemic

damage, put patients on course for a better and more complete recovery.

New techniques, such as tissue engineering to provide reconstructive surgery, are increasingly focused on quality-of-life outcomes. In 2004, doctors at Kiel University in Germany succeeded in growing a new jaw bone with a healthy blood supply for a man who had undergone an extensive tumour surgery and radiotherapy, using bone mineral blocks, recombinant human bone morphogenic protein (BMP) and liquid bone marrow containing stem cells. After eight years of eating soup and soft food, the 56-year-old man was able to tuck into sausage and bread for the first time.

Surgeons used computer-aided design to build the new mandible and then grew it inside the patient's right-side latimus dorsi muscle, his body serving as a living bioreactor. When it was ready, the surgeons transplanted the jawbone, bridging a gap in his mandible of more than seven centimetres. Bone formation continued for eight months and the graft

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remained in place until the patient's death from a heart attack 15 months later.

In a commentary in *Biomaterials*, Warnke and his team said, "The patient reported an improvement in both quality of life and self-confidence. He raised his body weight from 60 to 65 kg and he took part in family functions again. Prior to our reconstruction he had isolated himself out of embarrassment due to his inability to chew solid meals and socially inappropriate noises and mess due to anaesthesia of his lower lip. . . . Following transplantation his speech and tongue mobility improved and he found pleasure again in talking to friends on the phone. His mood turned from one previously of depression and suicidality to one of excitement and optimism."

Similar techniques are being used to rebuild noses after surgery, and hold great hopes for facial reconstruction, and for reconstructing palates after surgery.

Frans Hilgers and Annemieke Ackerstaff from the Netherlands Cancer Institute, carried out a review of patients who had had their larynx removed during cancer treatment. They found that rehabilitation focused almost exclusively on regaining speech. However, laryngectomy removes not only the 'voice box' but part of the respiratory system connecting the upper and lower airways, so that patients lose the ability to breathe through the nose. This leads to shortness of breath, coughing, excessive sputum production and loss of a sense of smell.

They concluded (*Folia Phoniatr Logop* 52:65–73) that prosthesis combined with good rehabilitation allowed patients to recover better speech and addressed their other problems. "The three main adverse side-effects of the surgical procedure, i.e. loss of natural voice, loss of the protective function of the larynx for the respiratory system and the loss of olfactory acuity due to the absence of a nasal air stream, should all be addressed in a complete rehabilitation program."

High-tech interventions will prevent and resolve some long-term problems. But there is also growing

concern about former patients who were damaged by radiation therapy and who suffer pain, restricted movement and exhaustion many years after treatment. Rehabilitation cannot therefore be seen simply as a short-term intervention following treatment. Indeed, there is a backlog of 'legacy' damage suffered by people who were treated 20 years ago or more, for whom a long-term rehabilitation programme is desperately needed. Few in Europe have access to such services, and this will become an increasing challenge for policy makers.

WHEN SHOULD REHABILITATION BEGIN?

Göran Laurell, head of the ear, nose and throat clinic at the Karolinska University Hospital, Sweden, believes there may be advantages in involving patients in their own physical rehabilitation almost as soon as they receive their diagnosis. His department piloted a trial in Stockholm, which is now being evaluated.

In an article in the Swedish Cancer Foundation magazine *Rädda Livet* Laurell says, "We teach patients to take responsibility for their rehabilitation from the start. It is our hope that some of them will achieve better function in the gullet, jaw and neck and shoulder muscles. We also hope that this will help them get their strength back more quickly."

This rehabilitation team includes a physiotherapist, psychologist, dietician and speech therapist and social worker as well as the medical team.

Polly Nikolaidis, the physiotherapist, teaches patients to strengthen the back of their throat and to look out for signs of problems in the jaw joint, which can often follow radiotherapy.

Speech therapist Therese Engström deals with voice, speech and swallowing. She meets patients before they are treated with radiotherapy or surgery. "I prepare them for the sort of problems that can arise during their treatment and I give them information and exercises that can pre-empt a lot of problems."

Laurell says patients have different needs and getting to know them is part of the art of providing care. He anticipates that the pilot may show that, for

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some patients, starting rehabilitation this early could prove too demanding. “It is important to have an individual approach to the rehabilitation of each patient. They have got tough treatment to go through and there are loads of people around them all the time. Some patients get too little space for themselves.”

Irene Korstjens believes that the timing should depend on the patient and the state they are at. The best time for the programme she started is two to three months after treatment ends. This rehabilitation builds on the natural recovery process.

But there is also a need for a second line of support. After the immediate treatment and recovery period, patients often emerge from a period of intense activity into a landscape where they seem to be facing the future alone.

Ciarán Devane, chief executive Macmillan Cancer Support, points out that in the UK the average cancer patient makes 53 visits to a health facility during their treatment, but this activity can stop very suddenly. “Six months after the end of treatment people tend to feel abandoned. What is the intervention that will help with that?”

Certainly women who have been treated for breast cancer need ongoing support, says Stella Kyriakides, President of Europa Donna Cyprus. “The level of anxiety does seem to increase as women finish treatment and move away from frequent contact with their breast team. While you are in treatment and you are the centre of attention, you have plenty of opportunities to voice your anxieties. As you are over the treatment and left on your own, the levels of anxiety seem to go up.

“We need to think of follow-up as an ongoing process for patients and their families. We need to address quality-of-life issues and side-effects, not only in the acute treatment phase. Often they are not addressed to the extent we would want, especially in some groups of patients, such as older patients.”

Heinz Ludwig, head of the Department of Medicine and Medical Oncology at Wilhelminen Hospital, Vienna, says that some long-term problems only

emerge after the priority – to guarantee survival – appears to have been achieved.

“As we learn more about the late consequences of treatment, there are secondary cancers but also several other delayed consequences like sexual dysfunction. This is a major concern in patients with breast cancer, which is frequently not adequately addressed. It is something that is still taboo, so patients are afraid to discuss it with their physicians and care givers. In my opinion, support for this problem is part of the service that we need to provide. It is not essential to have this service in the oncology centre – it could be somewhere else – but it is essential to offer it.”

THE POLICY CHALLENGE

Post-treatment plans, link nurses and support groups all play a vital role in the longer term follow-up of cancer patients. Survivors also need a proactive way back into the system if new problems emerge or symptoms do not improve. One of the key messages that emerges from the testimony of people who have suffered late effects is that many feel cut off from avenues of support.

But if health rehabilitation requires interdisciplinary teamwork within the health system, it is a still greater challenge to include social care, housing, employment rights and to challenge stigma. Despite many countries passing laws to try to prevent disability discrimination at work, it is clear that many people with cancer lose their jobs or unnecessarily give up their jobs. This can be a huge blow, because, in addition to providing an income, work also offers security, normality and self-esteem – issues often mentioned as important by cancer patients.

Increasingly, these broader issues are being taken up at policy level. In 2003, the French National Cancer Plan pioneered legal measures to give people with cancer better access to loans and insurance and more time to return to work.

The new Cancer Reform Strategy for England, launched in December 2007, includes a National

Cancer Survivorship Initiative designed to improve services for those who have finished their treatment. Mike Richards, National Cancer Director for England, and Macmillan Cancer Support, the charity that employs Macmillan nurse specialists, will jointly launch the initiative in March 2008.

Although this is still a paper policy, it has been endorsed by the British Prime Minister, Gordon Brown, and is expected to include:

- Follow-up by hospital doctors, nurses and general practitioners to check for recurrence or any late effects of treatment
- Education, self care and expert patient programmes
- Proactive case management, with patients using electronic technology to report on their wellbeing, and automated surveillance systems to ensure that tests are done at the right times
- Drop-in centres for peer support
- Rehabilitation programmes
- Psychological and spiritual support
- Back to work support and access to financial and benefits advice
- Nutritional advice
- Support for carers



ROLF LARSSON

Devane, of Macmillan Cancer Support, characterises the Cancer Reform Strategy as ‘ground-breaking’.

“We use the word groundbreaking because we really do believe that the Cancer Reform Strategy, as an evolution of the original Cancer Plan, has made it clear that we are talking about holistic cancer support along the whole journey, not just clinical and medical. For example, if we have a care pathway to cover the clinical side, what is the care pathway to cover the emotional support as somebody moves through the cancer journey?”

Expert hands. After finishing her medical treatment, this lung cancer patient spent time in Fenix, a specialist establishment in the south of Sweden, which provides a variety of physical and psychosocial support to cancer survivors

Funding on a sizable scale will be needed to provide a long-term survivorship plan for each patient that includes social as well as clinical care. However, the fact that survivors merit a whole section in the reform plan represents a shift in the thinking of policy makers.

The challenge will be to turn these aspirations into reality.

A key message from people who have suffered late effects is they feel cut off from avenues of support