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## **CARING FOR CANCER SURVIVORS**

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## **CARING FOR CANCER SURVIVORS**

### **LEARNING OUTCOMES**

After working though this article you should be able to:

- Discuss the meaning of the term 'cancer survivor'
- Recognise the possible long term and late effects of cancer in adults and its treatment
- Identify current policy initiatives related to cancer survivorship
- Discuss the needs of adult cancer survivors and their families
- Discuss the importance of promoting healthy lifestyles and supporting self-management in adult cancer survivors

Advances in scientific knowledge, detection, enhanced treatment regimes and management of acute treatment toxicities mean that the number of people living with and beyond cancer is increasing. Indeed approximately 2 million people are now living with cancer in the United Kingdom and two thirds are over sixty five<sup>1</sup>. **Insert figure 1 here** As the incidence of cancer rises and mortality falls the number of people living with and beyond cancer will grow. Indeed, it has been estimated that the number of cancer survivors is likely to be about 3 million in England by 2030<sup>2</sup>. Thus the burden of cancer is likely to rise, particularly when considered in tandem with the ageing population.

Many people will live a healthy and long life following cancer and its treatment. For example, the majority of men diagnosed with testicular cancer do not experience recurrent disease. Even those with secondary cancers can now live for many years. However for other survivors the diagnosis of cancer and/or its treatment can bring about a wide range of physical and psychosocial problems<sup>3</sup>, second cancers and more general issues relating to life after cancer. Some of these problems may not diminish over time and may even emerge long after treatment has ended.

As such, for many, cancer is akin to a long-term chronic illness. Indeed similarities between the health profile and needs of cancer survivors and those with other chronic illnesses have been noted. Nevertheless, it is important to acknowledge that there are aspects of living with cancer which are unique<sup>4</sup>. However, once active cancer treatments or follow up have ended, many of these individuals and their

families are betwixt and between, 'lost in transition,'<sup>5</sup> yet often needing ongoing and sometimes long-term support.

Arguably as cancer survivors spend the majority of their time in their own homes, the contribution of primary care practitioners is significant here on a number of levels, including, for example:

- Recognising and understanding the actual and potential needs of cancer survivors and their families;
- Promoting and supporting health, well-being and active lifestyles to prevent or minimise the late effects of treatments or second cancers;
- Monitoring for and promoting the early detection of recurrent disease/ second cancers and/or late and long term effects of cancer treatments;
- Providing relevant up-to-date information;
- Supporting individual's participation in decision-making, care planning and self-management;

However, although most cancer care now takes place in the community setting, historically the organisation and delivery of cancer services in the United Kingdom is such that not all primary care practitioners will have experience of caring for cancer survivors and their families. Furthermore it is possible that many primary care practitioners have not received education or training about issues surrounding cancer survivorship. Therefore it is likely that there is a need for additional education and training. Furthermore people need assurance that they can still access specialist service if required. Consequently coordinating care and support across the interface of primary and secondary health and social care and the third sector is important.

## DEFINING CANCER SURVIVORSHIP

### ACTIVITY

- **What does the term cancer survivorship mean to you?**
- **Who are the cancer survivors?**
- **What is the impact of cancer survivorship on patients, families and professionals?**

For some, cancer survivorship is equated with having successfully recovered from cancer and its treatment. However given the dynamic and multifaceted nature of problems individuals experience over time, this is a rather simplistic interpretation. A rather more encompassing definition, which considers the individual as a cancer

survivor **across** the illness trajectory, from the point of diagnosis until death, is used by the National Cancer Survivorship Initiative (NCSI) and the Department of Health.

Hence survivorship is conceived in terms of living with and beyond cancer<sup>6</sup> and its treatment. This draws attention to the idea that cancer survivorship is a lifelong journey, dimensions of which have been clearly outlined by Doyle<sup>7</sup>. Nevertheless this interpretation excludes those important to the individual who may also be affected by the diagnosis of and treatment for cancer, namely, families, partners, friends and carers. For instance, research has shown that female partners of men with prostate cancer experience rates of depression twice that of women in their local community, and higher than rates reported by their partners<sup>8-9</sup>.

## THE LONG TERM AND LATE EFFECTS OF CANCER

### ACTIVITY

- What are your education needs in terms of cancer care?

The long term and late effects of cancer are generally taken to refer to the physical, psychological and socioeconomic consequences of cancer and/or its treatment on survivors' health, wellbeing and quality of life. It seems rather ironic that the treatments which have contributed to improving cancer survival may have adverse physical effects on health, for example, osteoporosis, lymphoedema, fatigue and premature menopause, which may disrupt their everyday lives and life quality. For instance, in a recent study<sup>10</sup> several participants reported how fatigue made it difficult for them to manage work. Furthermore, although little is currently known about long-term psychosocial repercussions<sup>7</sup>, faced with uncertainty regarding their future<sup>11</sup>, fear of recurrence<sup>12</sup> and concerns regarding finance<sup>13</sup> and the possibility of returning to work, many cancer survivors experience psychosocial problems. For some the psychosocial problems may outweigh the physical difficulties. Moreover long term survivors, for instance those with head and neck cancers<sup>10</sup> may be particularly vulnerable.

Not everybody will experience these problems. Furthermore the effects vary from one individual to another depending on a range of variables, including diagnosis, treatment, age at and time since treatment. However, frequently people are either

inadequately or not informed at all about their possibility.<sup>14</sup> In part this may be associated with the focus of health professionals on immediate cancer treatment and the rather limited recognition in the past of the long term repercussions of cancer and its treatments. Nevertheless, as the impact of cancer treatments can continue long after treatment ends, it is important that health professionals are aware of these implications if patients are to receive the necessary support and care to maximise their well-being and life quality.

Long term effects of treatment are those which begin during cancer treatment and may persist for some time following treatment completion. Common examples of these effects include peripheral neuropathies and 'chemo-brain' (inability to concentrate) associated with certain chemotherapeutic drugs, fatigue and psychological distress.

By way of contrast late effects of treatments may not manifest for many years following the completion of cancer treatments<sup>2</sup>. These effects are associated with surgery, chemotherapy and radiotherapy. Moreover in terms of chemotherapy and radiotherapy effects depend on the drugs used and the part of the body irradiated. Quite clearly the impact of cancer continues beyond treatment completion. Moreover as new treatments emerge it is likely that new problems may also appear.

By way of example, survival rates in prostate cancer continue to improve, with 10 year survival rates reaching 77% for men diagnosed between 2001-2006 in England.<sup>15</sup> More than three quarters of men diagnosed with prostate cancer now survive beyond 5 years.<sup>16</sup> Similarly survival rates for breast cancer, the most common cancer in the United Kingdom, have been increasing steadily, with 5 year survival rates estimated to reach at least 80%.<sup>15</sup> However, the long term and late effects of cancer treatments [**Insert Tables 1 and 2**], can have profound long-term repercussions for individual's quality of life and relationships.

## THE NEEDS AND PRIORITIES OF CANCER SURVIVORS

High quality care is dependent on a clear appreciation of the needs and priorities of survivors. Yet interestingly findings from a recent study conducted in Wales suggested that the clinical, or condition, rather than a person centred service prevailed.<sup>17</sup>

It is widely acknowledged that people living with and beyond cancer have a range of physical, psychosocial, financial and spiritual needs<sup>18</sup>. However given different

treatment modalities for different cancers, together with individual coping strategies, age, gender, ethnicity, social support and spirituality, inevitably needs vary within and across cancer types and even over time. Indeed no two people with have the same needs. Nevertheless the NSCI<sup>2</sup> has identified a number of needs common to most individuals. **[Insert table 3 here]**

## **SUPPORTING CANCER SURVIVORS AND THEIR FAMILIES**

The needs of cancer survivors' is now a priority issue across all governments of the United Kingdom. In England following the publication of the Cancer Reform Strategy<sup>19</sup> the National Cancer Survivorship Initiative (NCSI) was established specifically to enhance services and support for this group of people. The initiative aims to ensure that as far as possible cancer survivors are able to lead healthy, active lives. Moreover it is recognised that to achieve this new and innovative approaches to care delivery are required. Thus, the initiative has set out a number of 'shifts' which are necessary to enhance the survivorship experience. **[Insert table four here]**

### **ACTIVITY**

- The National Cancer Survivorship Strategy can be viewed at [www.nsci.org.uk](http://www.nsci.org.uk)
- A number of initiatives are being tested across the country – find out what is happening in your local area/ region and share information with your colleagues.

Whilst specialist nurses have a vital and valuable role to play in supporting cancer survivors, primary care practitioners, particularly nurses and GP's, are ideally placed to work alongside and support cancer survivors and their families in the community setting, especially (but not exclusively) beyond the 'treatment phase' and in the longer term. Indeed this is recognised in the NCSI initiative. Personalised care is essential and key areas of support relate to the interrelated themes of:

- supporting self-care and self-management;
- sharing information
- promoting healthy lifestyles;

## Supporting self-care and self-management

These closely related concepts are core components of chronic disease management and focus on the individual's role in maintaining, sustaining or enhancing health<sup>20</sup> in collaboration with health professionals [Insert box 1]. In the context of cancer survivorship, a model of supported self-management is privileged and has been described as 'awareness and active participation by the person in their recovery, recuperation, and rehabilitation, to minimise the consequences of treatment, promote survival, health and well-being.'<sup>21</sup> Informed by the successes of approaches to self-management in chronic conditions, this model of care necessitates the development of collaborative partnerships between patients, their families and professionals.

### ACTIVITY

- What self-management activities are promoted in your area of practice?
- Take some time to look at what these courses offer.
- In what ways might these be adapted to support the needs of cancer survivors?

Evidence from North America suggests that patients may benefit from supported self-management for physical, psychological and emotional problems both during and after cancer treatment<sup>22</sup>. In the United Kingdom a number of specifically designed initiatives for cancer survivors have been developed.[Insert box 2] Whilst some are professionally led, others are facilitated by expressly trained lay people who have been treated for cancer.

It is widely recognised that relevant information is important in enabling people to cope with cancer and to make informed decisions<sup>23-24</sup>. To engage in self-management patients need access to relevant, reliable and balanced information. Moreover information needs to be culturally appropriate and sensitive and available in a range of formats to accommodate language and literacy<sup>25</sup>. However analysis of 1284 completed questionnaires during a recent patient experience survey<sup>26</sup> found that 43% of patients desired more information about life after cancer. The most frequently raised issues were in relation to information regarding:

- Side effects or indicators of recurrent disease (27%)
- Psychological or emotional aspects (14%)
- Diet and exercise (15%)

Although much more research is needed, emerging evidence indicates that healthy lifestyles, notably diet, not smoking, and exercise may influence the rate of cancer progression, enhance quality of life and improve survival<sup>2</sup> across all age groups. Furthermore lifestyle changes may contribute to reducing the risk of developing second cancers or other chronic health problems or even mitigate co-existing chronic illness progression. Indeed co-existing chronic conditions, such as cardiovascular illness may impact on the patient's cancer experience.

In terms of promoting healthy lifestyles, potentially practice nurses have a significant role to play. Indeed nurses may be able to advise on aspects of health, wellbeing and lifestyle, for instance, nutrition and healthy eating, smoking cessation, relaxation and stress management, emotional wellbeing and exercise. Nevertheless, for many practice nurses this may be uncharted territory. Thus to provide high quality, effective care further education and training is likely to be needed to develop existing and new knowledge and skills.

### **Effective coordination of care;**

The NSCI visualises services which are delivered as near to the patient's home as is possible thereby further highlighting the potential contribution of primary care practitioners. Nevertheless people need to be aware and assured that they can call on specialist services as needed. Yet the Picker Institute survey<sup>26</sup> highlighted that 21% of patients did not know who to contact if they were concerned and 75% did not know who to contact outside office hours if they had a concern. One important development championed by the NSCI<sup>2</sup> and the Welsh Assembly Government<sup>27</sup> which may bridge this gap and further enhance care and support is that of the cancer key worker.

The cancer key worker would take a key role in coordinating the patient's care and promoting continuity, ensuring the patient knows who to access for information and advice. The key worker would help the person navigate the care system, and provide support and advocacy. Nevertheless changes in key worker are likely to be required at significant transition points in the individual's cancer journey. It is vitally important that primary care practitioners are aware of the cancer key worker initiative and its implementation in their localities.

## Conclusions

The increasing prevalence of people living with and beyond cancer means that cancer survivorship is a current priority of governments across the United Kingdom. Cancer survivorship is a journey which begins at diagnosis and is shrouded with uncertainty. The impact of cancer and the expanding range of treatment modalities cannot be underestimated or overlooked. As new models of cancer service organisation and delivery emerge primary care practitioners may find that they are increasingly called on to support cancer survivors and their families. With appropriate education and training this could be challenging yet stimulating and important role to fulfil. **[insert resources]**

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## RESOURCES

- **Macmillan Cancer Support**
  - <http://www.macmillan.org.uk/Home.aspx>
- **Maggies Centres**
  - <http://www.maggiescentres.org/>
- **Breast Cancer Care**
  - <http://www.breastcancercare.org.uk/>
- **Cancer Research UK**
  - <http://www.cancerresearchuk.org/>
- **Cancer Survivors**
  - <http://www.cancersurvivors.org.uk/>
- **Livestrong**
  - <http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Aftereffects-of-Cancer-Treatment>
- **Having fun after cancer**
  - <http://after-cancer.com/>

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## **Self-Assessment**

1. Why are more people now surviving cancer in the United Kingdom?
2. Why is the burden of cancer likely to rise as the population ages?
3. According to Doyle, what are the dimensions of cancer survivorship?
4. What is the difference between the long term and the late effects of cancer and its treatment?
5. What factors contribute to the limited recognition of long term and late effects of cancer and its treatment?
6. List four factors which may influence the patient experience of long term or late effects of cancer and its treatments.
7. Identify and describe four late effects of radiotherapy treatment
8. Identify and describe four late effects of chemotherapy treatment
9. Identify four common needs of cancer survivors and their families.
10. List the ways in which primary care professionals might contribute to the ongoing care and support of cancer survivors and their families.

## **Self assessment answers**

1. Advances in scientific knowledge, early detection, treatment modalities and better management of acute toxicities.
2. The incidence of cancer is greater in older people.
3. A process beginning on diagnosis, uncertainty, life changing experience, duality of positive and negative aspects,
4. Long term effects begin during treatment and may persist for some time after treatment ends. Late effects may not manifest for many years following treatment completion.
5. Focus on immediate treatment and cure, limited knowledge and recognition, patterns of follow up.
6. Age at diagnosis, time of diagnosis, cancer type, nature of treatment, coping mechanisms.
7. These depend on the site irradiated, but may include gastro intestinal, dental, cardiovascular or bladder problems.
8. These depend on treatment regimes but may include osteoporosis and fertility, central nervous system and lung problems.
9. Empowerment, information, financial advice, early detection of complications/ recurrence/ side effects.
10. Provision of information, support self-management, education regarding healthy lifestyles, coordination of care, excellent communication.

**Key words**

Cancer, survivorship, primary care, nursing.

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## **FIGURE I**

### **Numbers of people living in the UK who have had a cancer diagnosis**

	<b>UK</b>	<b>%</b>
<b>Male</b>	819,188	40.9
<b>Female</b>	1,183,328	59.1
<b>0-17</b>	15,073	0.8
<b>18-64</b>	729,181	36.4
<b>65+</b>	1,258,262	62.8
<b>Breast</b>	548 998	27.4
<b>Colorectal</b>	235, 816	11.8
<b>Prostate</b>	253, 436	12.7
<b>Lung</b>	63, 522	3.2
<b>Other</b>	900, 744	45
<b>Total</b>	2,002,516	100

Source: Maddams et al. 2009

**Table 1**

<b>TABLE 1. LONG TERM PHYSICAL AND PSYCHOLOGICAL EFFECTS OF TREATMENTS FOR PROSTATE CANCER</b>	
<b>TREATMENT</b>	<b>LONG TERM EFFECTS</b>
<b>Radical prostatectomy</b>	<b>Erectile Dysfunction</b> <b>Urinary symptoms</b>
<b>Radiotherapy and brachytherapy (internal radiotherapy)</b>	<b>Bowel problems:</b> e.g. frequent and/or loose bowel movements. These may be intermittent. <b>Urinary symptoms</b> e.g. difficulty passing urine/ slight incontinence <b>Erectile Dysfunction</b> <b>Tiredness</b> <b>Bladder neck obstruction</b>
<b>Hormone therapy</b>	<b>Mood swings</b> E.g., short temper; crying without provocation. These have been associated with the LHRH blocker, Zoladex. <b>Loss of libido</b> <b>Erectile Dysfunction</b> Particularly while taking Luteinising Hormone Releasing Hormone (LHRH) blockers which impede production of testosterone. Impotence may not be permanent for many men. <b>Hot flushes</b> Associated with LHRH blockers. <b>Tiredness</b> <b>Muscle loss</b> <b>Weight gain</b> Associated with long term use of hormones <b>Breast swelling and tenderness</b> Associated with high dose bicalutamide.
<b>Cryotherapy and High Intensity Focused Ultrasound (HIFU)</b>	Erectile dysfunction Fistula Urinary problems
<b>General</b>	Loss of control Loss of sense of identity Impact on relationship with partner Impact on lifestyle and ability to work Depression

Source: NCSI 2009, p. 90

**Table 2****TABLE 2 LATE EFFECTS OF CANCER TREATMENTS**

TREATMENT	LATE EFFECTS
<b>SURGERY</b>	<b>Lymphoedema</b> A consequence of lymph node removal <b>Pain</b> <b>Digestion problems</b> Gastrointestinal surgery can lead to scar tissue formation/ absorption problems <b>Psychological distress</b> Associated with an altered body image/ self image and self esteem
<b>RADIOTHERAPY</b>	<b>Infertility</b> Associated with radiotherapy to testes, ovaries or total body irradiation <b>Dental problems: cavity and tooth decay</b> High dose radiation may cause gum disease and decrease the production of saliva <b>Heart or lung problems</b> Following radiotherapy to the chest wall <b>Gastro intestinal problems</b> <b>Bladder problems</b> <b>Brain, spinal cord and nerve problems</b> Risk of stroke with high does brain radiation <b>Second primary cancers</b> In areas subjected to radiotherapy
<b>CHEMOTHERAPY</b>	<b>Infertility</b> <b>Dental problems: cavity and tooth decay</b> Chemotherapy may adversely affect tooth enamel <b>Lung problems</b> May be associated with Bleomycin, Carmustine, Methotrexate <b>Osteoporosis</b> <b>Heart problems</b> May be associated with Adriamycin and Cyclophosphamide <b>Digestion problems</b> Methotrexate has an adverse effect on the liver <b>Brain, spinal cord and nerve problems</b> Hearing loss which may be associated with high dose Cisplatin <b>Second primary cancers</b>

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**Table 3: The needs and priorities of people with cancer**

<b>1</b>	Have the maximum chance of being cured
<b>2</b>	Return to as normal a life as possible.
<b>3</b>	Be empowered to take as much control of their own care as they wish
<b>4.</b>	Be given the information they require to help them make informed decisions
<b>5.</b>	Know what to expect and what to look out for
<b>6.</b>	Know who to contact should the need arise
<b>7.</b>	Know that the importance of side effects will be recognised and help given to them
<b>8.</b>	Know that any further disease or consequence of cancer treatment will be detected at an early stage.
<b>9</b>	Be offered and given the best treatments should they experience further disease or consequences of treatment
<b>10.</b>	Know that they can re-access specialist advice and care without delay should they so need
<b>11.</b>	Know that their anxieties and fears will be taken seriously and that they will have access to emotional support if they want it
<b>12</b>	Know that they will be given advice on financial benefits and on returning to work, education or training should they need this.
<b>13</b>	Know that health and social care will work effectively together so that their care is seamless and well coordinated.
<b>14</b>	Know that care will be given as close to home as possible, recognising that some specialist services cannot be provided in all locations
<b>15</b>	Know that they will be given advice on living healthily to maximise their chance of remaining well for as long as possible.

**Source : NSCI 2010**

**TABLE 4. ACHIEVING IMPROVED CARE AND SUPPORT FOR CANCER SURVIVORS**

1	A cultural change in the approach to care and support for people affected by cancer – enhanced focus on recovery, health and well-being after cancer treatment.
2	A move toward assessment, information provision and personalised care planning.
3	Supporting self-management, based on individual needs and with the appropriate clinical assessment, support and treatment.
4	A change from a single module of clinical follow up to tailored support that enables early recognition of and preparation for the consequences of treatment as well as early recognition of signs and symptoms of further disease.
5	A new emphasis on measuring experience and outcomes through routine use of Patient Reported Outcome Measures (PROMs) in aftercare services

**Source: NCSI 2010**

## **Box 1**

### **Self care**

‘Care taken by individuals toward their own health and well being’ (Department of Health, 2005, p. 1).

### **Self Management**

The ability to manage illness by ‘undertaking tasks that are the traditional province of professionals’ (Wilson et al., 2006, p. 805).

## **Box 2: Examples of patient self-management initiatives in the United Kingdom**

### **Living with Breast Cancer**

This is a professionally led 4 week course designed to replace hospital based after care with patient initiated after care supported by a self management programme.

### **Moving Forward**

This research based resource pack, which includes a DVD featuring exercise programmes designed for people who have had breast cancer treatment, has been developed by the charity Breast Cancer Care. The pack is designed for patients approaching the end of hospital based breast cancer treatment.

### **Active Wellness Programme**

This is a physical activity programme available to survivors of breast, colorectal and melanoma cancers in Bournemouth. The programme involves two initial one to one consultations with a specially trained staff member in order to individually tailor the programme. Participants are called at three weeks to provide support and encouragement and a one to one review is held at twelve weeks to measure improvements and agree a plan of action. Additional group support is also available.

### **Macmillan's New Perspectives Programme**

This is a lay led six week self-management course based on Kate Lorig's Chronic Disease Self Management Programme and designed by Macmillan Cancer Support specifically for people with cancer. The course aims to improve the skills and confidence of participants to self-manage their condition and the challenges they face.