

cancer52
the common voice
for less common cancers

**Cancer52
&
NCSI research workstream
Less Common Cancers Consultation
9th June 2009**

Summary



www.cancer52.org.uk

Cancer52 was invited to participate in the NCSI research work stream to map the research questions relating to the survivorship needs of people affected by the less common cancers.

58 people attended a consultation event, including representatives from 23 of our member organisations. Members were encouraged to bring cancer survivors and/or their relatives and carers to the event; 29 people directly affected by the less common cancers were present on the day. We used the Knowledge Café model to manage the sharing of information.

The discussions were structured according to the survivorship stages and cross-cutting themes of the NCSI pathway model but it is apparent that the pathway does not accurately reflect the journey for all of those affected by the less common cancers.

A broad range of issues emerged on the day and are summarised in a full report. Some issues are particular to the less common cancers including:

- Diagnostic delays as a result of low awareness amongst GPs as well as the general population of the symptoms of the less common cancers.
- The lack of specialist centres for the treatment of many of the less common cancers and the impact this has on treatment and organisation of care.
- The lack of effective second line treatments for many of the less common cancers. In some cases there are none that are recognised by the National Institute of Clinical Excellence.
- Difficulties in the workplace as a result of lack of awareness amongst employers and colleagues of the needs of people with less common cancers
- Feelings of isolation – people living with a less common cancer find it harder to network with other survivors in a similar situation locally.
- The physical effects of the disease and treatment and the impact on self-image.
- The loss of fertility particularly associated with the gynaecological cancers and the impact on self-identity.
- The need for emotional support and/or psychological treatment to enable people affected by the less common cancers to live as full a life as possible.
- Limited access to key services that are routinely available for patients affected by the more common cancers – including access to counselling and psychological services.
- The lack of support and information for people caring for those with less common cancers.

A number of research questions addressing the above issues were formulated.

Availability of specialist resources

There are fewer specialist resources available for the treatment and care of people affected by the less common cancers compared with those available to people affected by the four major cancers. There are fewer centres of excellence and this impacts on very many aspects of people's cancer journey. It has implications for the quality of care and treatment, including in the longer-term, but it has important practical and financial implications due to the distance that patients need to travel for treatment.

Work and finance:

- How far do people with less common cancers have to travel to get specialist care and what are the financial implications of this? Is there any financial support available?

Self-management:

- How does the quality of support vary around the UK, especially away from specialist centres i.e. if people live a long way from a specialist centre, and source of specialist support, how do they get the support they need to self-manage their condition? Are there minimum standards of care?

Commissioning:

- How does the provision of specialist services for the less common cancers match levels of incidence and prevalence and appropriate geographical coverage?
- Is the commissioning system working effectively for specialist services where several commissioners are pooling resources? Is it working effectively for the less common cancers, especially at a local level for specialist needs?

Organisation of care for continuity and co-ordination of services

To a large extent, this is related to the point above – if patients aren't under the care of a centre of excellence (or if the centre of excellence is remote geographically) their care is likely to be more patchy.

Remission

- How can we promote better co-ordination between the different groups of health care professionals that could play a role in the early detection of recurrent cancer?
- What guidelines exist for the follow-up care of people with a less common cancer?
- What is the most appropriate means of follow-up and who is the most appropriate person to take the lead?

Active/advanced disease

- How can tertiary NHS/social services best respond to the rapidly changing health and personal circumstances of patients with active/advanced cancer and their families?
- What is the best structure for care of the patient beyond the hospital team? Who should assume primary responsibility for the patient?

Remains well

- What are patients' needs post formal follow-up. How do they get back into the 'system'?

Second and subsequent treatments:

- What, if any, systems are in place to ensure continuity of care for patients undergoing second and subsequent cancers? Is there less continuity for patients with less common cancers?

Long-term effects

- What ongoing services exist to support patients dealing with the long-term effects of cancer? What is the most appropriate infrastructure for delivery of such support?

Self-management

- To what extent are patients and families given the support they require? Is the infrastructure properly designed to maximise patient welfare?

Treatment options

Treatment options are more limited for the less common cancers than for the major four, reflecting the paucity of research into many of these conditions. Clinical trials are non-existent for many of the less common types of cancer - due in part to the fact that there are simply too few patients to make trials meaningful.

Recurrence

- What further treatment options exist for treating recurrence of the less common cancers?
- What patient information is available on treatment strategies for the less common cancers?

Commissioning

- How do patients ensure that they are getting optimum treatment in cases where they cannot access a centre of excellence for their particular cancer?
- How much money is spent on research into different cancers?
- Is there a mechanism to translate therapies for the major cancers to treat the less common cancers?

Psychological issues

Psychological issues are relevant at every stage of the pathway as people struggle to deal with the impact of their cancer diagnosis and the effect that it is having on their lives and the lives of those around them.

Although there are positive aspects to cancer survivorship – a '*joie de vivre*' and a renewed appreciation of the value of life – patients face many ongoing issues on their cancer journey. Patients often use the term '*post traumatic stress*' to describe the psychological aftermath of their illness and talked about 'anticipatory grief'.

Isolation is an issue particularly affecting people with less common cancers – since these people are less likely to meet others with the same diagnosis. Self-image issues are also important because of the nature of certain of the less common cancers and the treatments for them.

Self-management

- Is there any support available to help people come to terms with changes in their body image/appearance? How effective is it?

Remains well

- How do people with less common cancers get help with creating their 'new normal' and adjusting to it? What psychological services are available to help them?

Long-term effects

The long-term effects of the less common cancers and the treatments for them are generally less well characterised than for the major cancers.

- What are the long-term effects of the less common cancers and the treatments for these? How are these being monitored in individual patients?
- What is the incidence of lymphoedema following all types of cancer including the less common cancers?
- What ongoing services exist to support patients dealing with the long-term effects of cancer? What is the most appropriate infrastructure for delivery of such support?
- What role could complementary therapies play in the management of the long-term effects of cancer?

Informing others

In comparison with the four major cancers, there is less awareness and understanding of the less common cancers – amongst groups including health and social care professionals, benefits staff and employers. This leads to a greater social stigma, increased levels of discrimination and problems returning to work, securing benefits etc.

- What are the information needs of i) benefits staff; ii) educational establishments; iii) employers; and iv) GPs and other health care professionals to help them support people affected by cancer?
- How can information be delivered effectively to these groups?

Genetics

This is an issue that relates to specific cancers including Retinoblastoma.

- Where cancers are known to have a genetic component, what information is given to patients regarding i) the risk of developing a second cancer and ii) the risk of their children (or future children) developing cancer?
- Are there any measures in place for long term monitoring of these patients (and their children)?
- How can GPs and health professionals be made aware of the risks?

Children and young people

Children and young people face some very specific issues. Cancers in children and young adults are rare – the most common being childhood leukaemia which affects some 500 children a year in the UK.

There is concern about the child's knowledge and awareness of their condition. This will obviously vary according to their age at diagnosis and there is likely to be wide variation in the amount of information given by parents to children either at the time of treatment or later in life. This has important implications for self-management especially with regard to detection of recurrence or second cancers.

Continuity of care is an important issue for children with cancer – it is unclear how much cross-over exists between paediatric and adult services.

Children can face great difficulties in returning to education after a cancer diagnosis. They may have missed out on a considerable amount of schooling, they may be left with long-term physical, psychological and cognitive problems as a result of their illness and treatment and they face being stigmatised when they return to the school setting.

The long-term effects of cancer can be very significant for children as they are still developing, not just physically but mentally and socially. Chemotherapy and radiotherapy can affect their growth, it can cause neurological damage in some children and other serious physical problems including heart problems. The child will have to carry these effects with them through the rest of their childhood and through the whole of their adult lives.

Information

- At what age do children get told full information about their condition?
- What are the information needs of [educational establishments] to help them support [children] affected by cancer?

Remission/follow-up

- What cross-over exists between paediatric and adult services?

Work/finance

- What is the appropriate level of support to enable children to return to education?

Long-term effects

- What are the long-term effects of the less common cancers and the treatments for these? How are these being monitored in individual patients?

Self-management

Is there any self-management support for children to get back into education?

Caregivers

The needs of caregivers can often be overlooked but they are survivors of a cancer diagnosis as well. All of the issues raised above relating to the less common cancers make the journey more difficult for the caregiver as well as the cancer patient.

The fatigue, depression, grief and challenges of day-to-day living which are often faced by a patient diagnosed with cancer can also be experienced by that patient's caregiver.'

As well as having the functional ability to look after the patient's physical needs, the caregiver must have the emotional health to deal with the psychological issues and the physical sequelae of the cancer.

There is a need for a programme of support and information specifically targeted at care-givers with the following suggested components:

A 'systems navigator' to help steer patient, caregiver and family through the maze of post-operative care, providing guidance on securing benefits where appropriate, providing information on the practical aspects of day-to-day living (both for the patient and the caregiver) and also signposting to organisation and agencies who

might be able to assist or answer questions related to the cancer survivorship journey.

More studies and counselling for “anticipatory grief” with information on coping mechanisms and support systems that can be provided to caregivers.

More education about critical skills for caregivers. This could include practical skills such as how to lift a patient properly without risk of damage to the patient or caregiver; how caregivers can communicate better with doctors; how caregivers can be better supported if they are suffering from depression; tips for caregivers about maintaining their own health; readily available respite care information; support groups for care givers etc.

More education for doctors on how to deliver bad news. Frequently both the patient and the caregiver are given the news of a cancer diagnosis together at the same time. The words used by the doctor become imprinted on the mind of both patient and caregiver and if not delivered in an appropriate, sensitive manner can literally scar the attitudes of patient and caregiver towards survivorship and living with cancer.

Remission/follow up

How can people (both patients and caregivers) be supported in dealing with the psychological impact of their diagnosis? Specifically, what support systems and coping mechanisms would help them to deal with ‘anticipatory grief’ and to adjust to their ‘new normal’?

Information

What are the specific information needs of caregivers? And what is the most effective delivery mechanism for information to caregivers?

**For the full report please contact the Cancer52 secretariat:
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Cancer52 member organisations

Organisation

Adam's Hats
AMEND
Barrett's Oesophagus Campaign
Brain Tumour UK
British Lymphology Society
British Thyroid Foundation
Butterfly Thyroid Cancer Trust
Cancer Laryngectomy Trust
Cancer of Unknown Primary Foundation
Childhood Eye Cancer Trust
Children with Leukaemia
CLIC Sargent
CML Support Group
CORE (Digestive Disorders Foundation)
International Brain Tumour Alliance
Jo's Trust
Leukaemia CARE
Lymphoedema Support Network
Lymphoma Association
Maggie's Cancer Caring Centres
Meningioma UK
Mouth Cancer Foundation
Myeloma UK
Myrovlytis Trust
NET Patient Foundation
Neuroblastoma Society
Oesophageal Patients Association
Orchid Cancer Appeal
Ovacome
Ovarian Cancer Action
Pancreatic Cancer UK
Rarer Cancers Forum
Samantha Dickson Brain Tumour Trust
Sarcoma UK (part of The Sarcoma Trust)
Target Ovarian cancer
Teenage Cancer Trust
The Eve Appeal
Wellbeing of Women

Web Address

<http://www.adamshats.org>
<http://www.amend.org.uk>
<http://www.barrettsfoundation.org.uk/>
<http://www.braintumouruk.org.uk/>
<http://www.lymphoedema.org>
<http://www.lymphoedema.org>
<http://www.butterfly.org.uk/>
<http://www.cancerlt.org/>
<http://www.cupfoundjo.org/>
<http://www.chect.org.uk>
<http://www.leukaemia.org>
<http://www.clicsargent.org.uk>
<http://www.cmlsupport.org.uk/>
<http://www.corecharity.org.uk/>
<http://www.theibta.org/>
<http://www.jotrust.co.uk>
<http://www.leukaemiacare.org.uk>
<http://www.lymphoedema.org>
<http://www.lymphoma.org.uk/>
<http://www.maggiescentres.org>
<http://www.meningiomauk.org/>
<http://www.mouthcancerfoundation.org/>
<http://www.myelomaonline.org.uk>
<http://www.myrovlytistrust.org>
<http://www.netpatientfoundation.com>
<http://www.adamshats.org>
<http://www.opa.org.uk/>
<http://www.orchid-cancer.org.uk>
<http://www.ovacome.org.uk>
<http://www.ovarian.org.uk>
<http://www.pancreaticcancer.org.uk>
<http://www.rarercancers.org.uk/>
<http://www.braintumourtrust.co.uk/>
<http://www.sarcoma-uk.org/>
<http://www.targetovarian.org.uk/>
<http://www.teenagecancertrust.org>
<http://www.eveappeal.org.uk>
<http://www.wellbeingofwomen.org.uk>

Cancer52 is a consortium of organisations representing the less common cancers, so named because 52% of cancers deaths are from the less common cancers¹. Cancer52 has 38 member organisations .

¹ Office of National Statistics 2004