
Survivorship Guidelines

September 2013 (updated August 2015)

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1 Introduction

In September 2013, the LCA Survivorship Pathway Group published guidelines which were used as a basis for the survivorship sections in the tumour specific LCA clinical guidelines as well as being a stand-alone document. Since then, further work nationally and locally has been published and reported, making it a suitable time to update the guidelines. The importance of good survivorship care is well known: people living with and beyond cancer that have unmet needs are 20% more likely to visit their GP and twice as likely to attend A&E as those who haven't had a cancer diagnosis. They are more likely to be unemployed and many report economic hardship. The aim of these guidelines is to provide a framework to help healthcare professionals and Trusts implement best practice evidenced based survivorship care.

2 Background

As cancer survival rates improve, cancer is increasingly being viewed as a long term condition. More is known about the long term consequences of cancer and its treatments, and healthcare professionals working in cancer services should be able to provide first-line assessment and interventions for a wide variety of physical and psychological conditions and know when and how to refer onto relevant experts.

The National Cancer Survivorship Initiative ran from 2008 to 2013, providing a clear drive for a shift in the way in which services are provided to those living with and beyond cancer. The NHS England/Macmillan Cancer Support's 'Living With and Beyond Cancer Programme' is seeking new ways to further implement and embed good survivorship care. The Recovery Package is a key aspect, and three of its four components should be offered by acute cancer services.

- A Holistic Needs Assessment (HNA) offers an opportunity to discuss the things which are important to the person.
- A treatment summary provides the person and their GP with details of what treatment they have had to date, signs and symptoms of recurrence, plans for follow-up, likely consequences of the cancer and its treatment and what to do if these arise, and details of their key worker.
- A health and well-being event provides an opportunity to learn, in a group setting, about things which are relevant to the cancer and its treatment.

Achieving world-class cancer outcomes: A strategy for England 2015-2020 is the newly published report by the Independent Cancer Taskforce. It recommends that every patient has access to all aspects of the Recovery Package by 2020. There is already a requirement through commissioning intentions and subsequent contractual agreement for the use of the Recovery Package within London.

The current system of hospital based, routine follow up is not necessarily designed to best meet the ongoing needs of those living with and beyond cancer. Alternative models of follow-up, such as stratified follow-up and supported self-management, give the person and their GP a more central role.

The evidence base for healthy lifestyle behaviours highlights the benefits to those living with and beyond cancer of being able to access healthy lifestyle information, support and intervention. Healthy lifestyle choices improve not only cancer-related mortality and morbidity, but also all-cause mortality and morbidity. This is significant, as recently published evidence shows that approximately a third of people living with and beyond cancer have one other long term condition (LTC) and a further third have three or more. Healthy lifestyle behaviours have a proven impact on many LTCs, e.g. diabetes, cardiac disease and mental health disorders.

The mental health and psychological support needs of people who have had a cancer diagnosis have been under-recognised for many years. The evidence suggests that one in four of those who receive a cancer diagnosis will need some level of psychological support, with one in ten requiring specialist intervention from a psychologist, psychotherapist, psychiatrist or other psychological support professional.

The consequences of cancer and its treatments are multiple – emotional, physical, financial, psychological and spiritual. Early discussion of these consequences, from diagnosis onwards, is essential and should form part of treatment consent prior to treatment starting. The requirement for increased shared decision-making, where the person and their treating physician jointly agree the best treatment, gives early discussion of possible consequences further weight and priority. Early and ongoing discussion ensures that the risks of consequences are minimised when possible, recognised early if they manifest, and are addressed in a timely manner when necessary. Early referral to relevant specialist rehabilitation, including return to work or education, and to services which are able to manage consequences, minimises negative outcome, including poorer quality of life.

Achieving world-class cancer outcomes places an increased responsibility on both providers and commissioners to ensure suitable services, with an appropriately skilled workforce made available to support those living with and beyond cancer, even many years after initial treatment has ended. Healthcare professionals should be supported to recognise consequences and know how to access appropriate services. There should be clear and explicit pathways into early assessment and intervention for these consequences, locally when possible and at tertiary centres when necessary.

3 Recommendations and Rationale

The recommendations offered in this section are based on Macmillan Cancer Support's *What to do after cancer treatment ends: Ten Top Tips* (2014), which was developed by its Consequences of Cancer Treatment Collaborative (CCaT). They cover the key components of good survivorship care and lead to one or more recommendations, which can be found in bold below. Additional information comes from *Throwing light on the consequences of cancer and its treatment* (2013) and *Living with and beyond cancer: taking action to improve outcomes* (2013).

1. Discuss a person's needs

The Holistic Needs Assessment (HNA) has been shown to be effective in identifying a person's individual concerns. It can take many forms and the LCA has developed, in collaboration with *London Cancer*, a version (the pan-London tool) which includes a concerns checklist and a distress thermometer that allows people to specify issues that are of most concern to them. It covers physical, emotional, spiritual, financial, and welfare and practical concerns. Subsequent discussion with a healthcare professional provides an opportunity to explore the issues raised and to jointly agree how to best address them. This could include provision of information, intervention by that healthcare professional, referral to a specialist, or the person themselves taking action. Following the discussion, a care plan which outlines the agreed actions is completed as a record of the discussion.

Recommendations:

1. Every patient should be offered a Holistic Needs Assessment and associated care plan at key pathway points, including at diagnosis and end of treatment, and whenever a person requests one.
2. The use of the pan-London tool is strongly encouraged and can be found in Appendix 1 and here: <http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/forms-and-guidelines/lca-patient-experience-programme/>

2. Provide a treatment summary

A treatment summary is given to the person (unless they have opted out of receiving letters from the hospital) and their GP at the end of treatment or end of set of treatments. It provides a summary of the treatments received during that time, including planned follow-up and signs and symptoms of which to be aware. These symptoms include possible consequences of cancer and its treatment, signs of recurrence and other important information.

Recommendations:

1. A treatment summary should be provided to the person and their GP at end of a defined treatment or series of treatments, when being discharged from regular follow-up, or when changes are made to long standing treatment regimes.
2. The use of the NCSI treatment summary template is encouraged, and is embedded within both Somerset and Infoflex. A copy can be found in Appendix 2 and here: <http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/forms-and-guidelines/lca-patient-experience-programme/>

3. Provide a main contact

UK and England wide work including the national Cancer Patient Experience Survey has shown the necessity of a key contact, or key worker. People living with and beyond cancer, their GPs and other healthcare professionals, benefit from having a named person to contact if they need help or advice about issues related to consequences of cancer and its treatment.

Recommendation:

The treatment summary must include the details of the person's key worker and who to contact out of hours. This should be sent to the GP, the patient and any others whom the patient identifies as necessary.

4. Identify and make early referrals for consequences of cancer and its treatments

Cancer and its treatments have far-reaching consequences and those with associated unmet needs are more likely to access healthcare services than their age-matched counterparts. Providing information on likely post-treatment symptoms, e.g. early lymphoedema or faecal incontinence, and how these can be managed or avoided, allows people to seek the right help from the right people at the right time.

Where prompt questions for specific symptoms have been developed, these should be used to help identify when treatment and/or onward referral is indicated.

The LCA Survivorship Pathway Group is leading work to develop pathways for management of several consequences of treatment, which reflect NHS England (London)'s *Five Year Commissioning Strategy for Cancer* (2014): Completed guidelines for fertility, lymphoedema and referral to complementary therapy can be found here:

<http://www.londoncanceralliance.nhs.uk/information-for-healthcare-professionals/forms-and-guidelines/lca-patient-experience-programme/>

Guidelines on sexual consequences, gastro-intestinal (GI) consequences, endocrine symptoms and cancer rehabilitation service referrals will be published during 2015/6 and will be available on the LCA website.

Recommendations:

1. Information on possible consequences of cancer treatment and what to do if they occur should be routinely provided to all patients. This should be done from the time of discussion of treatment onwards, with the information clearly reiterated during the end of treatment consultation and in the treatment summary.
2. Written information should be offered to support any information given verbally.

3. When a person presents with symptoms indicative of a known consequence of cancer and its treatments use prompt questions and screening tools in order to treat, manage or make onward referrals to address these.

5. *Encourage people to talk about how they feel*

A cancer diagnosis has an emotional impact, with one in four people needing professional support as a result of anxiety or depression impacting on their quality of life, and one in ten experiencing symptoms severe enough to warrant interventions by a psychologist or psychiatrist in the year following diagnosis.

Recommendation:

Use an HNA including distress thermometer to help identify psychological distress, anxiety or other psychological support need. If a distress score of over 4 is recorded, the problem should be discussed with the person, and onward referral to psychological support services considered.

6. *Healthy lifestyle*

There is a strong body of evidence which supports the adoption of a healthy lifestyle for those who have had a cancer diagnosis.

Recommendation:

Individuals should be offered access to a health and well-being event (HWBE) to provide them with the information they need to help make healthy lifestyle choices

The LCA guidance on HWBE can be found here:

<http://www.londoncanceralliance.nhs.uk/media/100126/lca-guidance-on-health-and-well-being-events-may-2015.pdf>

- **Smoking cessation**

Tobacco smoking is the main cause of preventable morbidity and premature death in England.

Receiving a cancer diagnosis can give a 'teachable moment' where people may be more susceptible to health advice and hence more motivated to quit.

Recommendation:

All current smokers should be asked about their smoking habit at key pathway points, e.g. at diagnosis, after surgery and at follow-up appointments, and offered smoking cessation advice with onward referral to local services as necessary. Local services can be found here:

<http://www.nhs.uk/Service-Search/Smoking-cessation-clinic/London/Results/557/-0.085/51.511/636/13136?distance=25>

- **Diet**

The negative role that diet can play in cancer incidence has been widely documented and there is increasing evidence of its beneficial influence beyond treatment. These benefits are not only on cancer recurrence, but also on development of a second primary, as well as on cancer related and all-cause mortality and morbidity.

Nutritional issues during or following treatment include weight loss or gain; changes in body composition, for example loss of muscle mass; particular eating difficulties including swallowing problems or a limited capacity for food. There are also long-term consequences (e.g. changes in bowel habits for those who have had pelvic radiotherapy), with the aim of dietary advice therefore also being to counter adverse effects of cancer treatment.

The World Cancer Research Fund's (WCRF) Second Expert Report, *Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective* (2007), recommends the following eight point plan for all cancer survivors:

- Be as lean as possible within the normal body weight range.
- Be physically active as part of everyday life.
- Avoid sugary drinks and limit the consumption of energy dense foods.
- Eat mostly foods of plant origin.
- Limit intake of red meat and avoid processed meat.
- Limit alcoholic drinks.
- Limit consumption of salt. Avoid mouldy cereals or pulses.
- Aim to meet nutritional needs by diet alone.

Tumour specific updates made within the WCRF's programme of continuous update can be found here: <http://www.wcrf.org/int/research-we-fund/continuous-update-project-findings-reports>

Recommendation: Patients are provided with dietary advice, based on the WCRF recommendations at the end of treatment, with referral to specialist dieticians as required.

- **Physical activity**

There has been a dramatic rise in the amount of high quality published research on the role of exercise in cancer in recent years. Physical activity results in improvement in quality of life, fitness and function and in symptoms related to cancer and its treatments. It can reduce length of stay and improve cellular recovery post chemotherapy. It reduces cancer recurrence, incidence of second cancers and reduces both all cause and cancer-specific mortality.

There is international consensus that people living with and beyond cancer should exercise to the same level as the general population for health benefits. Research suggests that a combination of cardiovascular and muscular strength training has an important additional benefit over only undertaking either alone.

Recommendations:

1. People should be encouraged to maintain or increase their level of physical activity both during and after treatment in line with national guidance.
<http://www.nhs.uk/livewell/fitness/pages/physical-activity-guidelines-for-adults.aspx>
http://ncsi.org.uk/wp-content/uploads/EvidenceBasedGuidance_4_Br0566_WEB.pdf
2. Their need for support to increase or maintain their activity should be assessed, with referral to local exercise opportunities, such as exercise on prescription, considered.
<https://www.nice.org.uk/guidance/ph2>
3. They should be referred for specialist assessment by a physiotherapist as necessary.

7. Stratified, self-managed follow-up

There is a move towards increased self-management, with fewer hospital based appointments and a requirement for primary or local secondary care to respond to more routine issues. Research has shown that recurrence is more likely to be detected by the patient themselves between appointments, rather than during an outpatient appointment. This has clear benefits to people living with or beyond cancer, including reduced anxiety in the lead up to routine appointments and less interference in their day-to-day

life caused by having to attend hospital appointments. In addition, by reducing unnecessary appointments, Trusts are able to see new patients more quickly and spend more time with those with more complex needs.

For self-management to be effective, people living with and beyond cancer and their primary care providers need to be given the right information about signs and symptoms of recurrence, clear pathways to follow if they are concerned and guaranteed a fast, explicit route to re-access services if necessary.

Recommendation:

1. Treatment summaries, as described above, should be routinely used to provide the person and GP with details of planned follow-up.
2. Services should use LCA tumour specific guidelines to define those people for whom stratified follow up is clinically feasible and develop local policies and procedures to enable their roll out.

8. Encourage survivors to share their experience

Sharing the experience of living with and beyond cancer can be beneficial to the person themselves, carers, and others who have a cancer experience. Providing feedback on experience, volunteering and participation in research, can all impact on the person.

Recommendations

1. People living with and beyond cancer should be offered information on local support groups and where they can access further information on sharing experience.
2. Health and well-being events should be co-facilitated and run with those living with and beyond cancer whenever practicable.

Appendix 1: Holistic Needs Assessment



London Holistic Needs Assessment

For each item below, please tick **yes** or **no** if they have been a concern for you during the last week, including today. Please also tick **discuss** if you wish to speak about it with your health professional.
 Choose not to complete the assessment today by ticking this box

		Yes	No	Discuss	Yes	No	Discuss
Date:		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Name:		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital/NHS number:		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tick the number that best describes the overall level of distress you have been feeling during the last week, including today:							
10	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
9	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
8	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
7	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
6	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
5	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
4	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
3	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
2	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
1	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
0	<input type="checkbox"/>			<input type="checkbox"/>			<input type="checkbox"/>
Practical concerns							
Caring responsibilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing or finances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transport or parking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work or education	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Difficulty making plans	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grocery shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Preparing food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bathing or dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laundry or housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family concerns							
Relationship with children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship with others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emotional concerns							
Loneliness or isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sadness or depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worry, fear or anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anger, frustration or guilt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Memory or concentration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hopelessness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual concerns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spiritual concerns							
Regret about the past	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of faith or other spiritual concern	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of meaning or purpose in life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For health professional use							
Date of diagnosis:							
Diagnosis:							
Pathway point:							

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Appendix 2: Treatment Summary

GP Name
GP Address

Dear Dr X

Re: Add in patient name, address, date of birth and record number

Your patient has now completed their initial treatment for cancer and a summary of their diagnosis treatment and on-going management plan are outlined below. The patient has a copy of this summary.

Diagnosis:	Date of Diagnosis:	Organ/Staging Local/Distant
Summary of Treatment and relevant dates:		Treatment Aim:
Possible treatment toxicities and / or late effects:		Advise entry onto primary care palliative or supportive care register Yes / No
		DS 1500 application completed Yes/No Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team:		Contacts for re referrals or queries: In Hours: Out of hours:
		Other service referrals made: (delete as nec) District Nurse AHP Social Worker Dietitian Clinical Nurse Specialist Psychologist Benefits/Advice Service Other
Secondary Care Ongoing Management Plan: (tests, appointments etc)		
Required GP actions in addition to GP Cancer Care Review (e.g. ongoing medication, osteoporosis and cardiac screening)		
Summary of information given to the patient about their cancer and future progress:		
Additional information including issues relating to lifestyle and support needs:		

Completing Doctor: Signature:

Date:

National Cancer Survivorship Initiative



**WE ARE
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CANCER SUPPORT**



NHS Improvement

Appendix 3: Summary of Recommendations

Every patient should be offered a Holistic Needs Assessment and associated care plan at key pathway points, including at diagnosis and end of treatment, and whenever a person requests one.

- The use of the pan-London tool is strongly encouraged
- A treatment summary should be provided to the person and their GP at end of a defined treatment or series of treatments, when being discharged from regular follow-up, or when changes are made to long standing treatment regimes
- The use of the NCSI treatment summary template is encouraged, and is embedded within both Somerset and Infoflex
- The treatment summary must include the details of the person's key worker, and who to contact out of hours. This should be sent to the GP, the patient and any others whom the patient identifies as necessary
- Information on possible consequences of cancer treatment and what to do if they occur should be routinely provided to all patients. This should be done from the time of discussion of treatment onwards, with the information clearly reiterated during the end of treatment consultation and in the treatment summary
- Written information should be offered to support any information given verbally
- When a person presents with symptoms indicative of a known consequence of cancer and its treatments use prompt questions and screening tools in order to treat, manage or make onward referrals to address these
- Use an HNA including distress thermometer to help identify psychological distress, anxiety or other psychological support need. If a distress score of over 4 is recorded, the problem should be discussed with the person, and onward referral to psychological support services considered
- Individuals should be offered access to a health and well-being event (HWBE) to provide them with the information they need to help make healthy lifestyle choices
- All current smokers should be asked about their smoking habit at key pathway points, e.g. at diagnosis, after surgery and at follow-up appointments, and offered smoking cessation advice with onward referral to local services as necessary
- Patients are provided with dietary advice, based on the WCRF recommendations at the end of treatment, with referral to specialist dieticians as required
- People should be encouraged to maintain or increase their level of physical activity both during and after treatment in line with national guidance
- Their need for support to increase or maintain their activity should be assessed, with referral to local exercise opportunities, such as exercise on prescription, considered
- They should be referred for specialist assessment by a physiotherapist as necessary
- Treatment summaries, as described above, should be routinely used to provide the person and GP with details of planned follow-up
- Services should use LCA tumour specific guidelines to define those people for whom stratified follow up is clinically feasible and develop local policies and procedures to enable their roll out

- People living with and beyond cancer should be offered information on local support groups and where they can access further information on sharing experience
- Health and well-being events should be co-facilitated and run with those living with and beyond cancer whenever practicable