
Guidance on Health and Well-Being Events

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1 Introduction

Health and well-being events (HWBEs) are one of four components of the Recovery Package, alongside Holistic Needs Assessments (HNA), treatment summaries (TS), which are offered as people reach the end of a package of treatment for cancer usually by their treating hospital, and the cancer care review, which is carried out in general practice. However, various models of delivery of HWBEs have been found to be effective, and provision outside of the acute hospitals, in community or third sector settings, have also been positively evaluated.

As cancer is now being diagnosed earlier, and treatments are becoming more effective, the number of people living with and beyond cancer is growing; with a predicted rise to 4 million people in the UK by 2030, a 3% year-on-year rise. In 2012, the prevalence in the London Cancer Alliance population of around 5.7 million, or 8% of the UK population, was approximately 132,700, or 156,500 if those living over 20 years (as per the UK figures) are included. An increasing number will be expected to self-manage their day-to-day health needs, managing anticipated consequences with the support of their GPs, and only access secondary or tertiary services when signs or symptoms of recurrence arise, or for planned follow-up, such as scans.

The aim of a HWBE is to support people to be able to self-manage any anticipated ongoing health and social care needs as a result of their cancer or its treatments. It provides the opportunity to offer health promotion information at a point at which people are potentially open to making lifestyle changes: a 'teachable moment'. This information needs to be provided in a way which enables the person to assimilate it and make it relevant to them. Work led by the NCSI (National Cancer Survivorship Initiative) defined HWBEs as one-stop clinics where those living with and beyond cancer and their carers could acquire the information they needed at the end of treatment to support them to take an active role in their recovery.

2 Background

In 2014, the London Cancer Alliance (LCA) Survivorship Pathway Group completed a mapping of health and well-being events currently available within the LCA. This addressed several questions, such as how HWBEs were being defined, what models were being used to deliver them, what topics were being covered and how they were funded and staffed. The full report can be accessed here:

<http://www.londoncanceralliance.nhs.uk/media/91615/lca-health-and-well-being-events-mapping-january-2015.pdf>

The mapping report made various recommendations for further work, namely that the LCA Survivorship Pathway Group should:

- agree a definition for health and well-being events within the LCA. This should include what a HWBE is not as well as what it is
- agree a minimum generic content standard
- work collaboratively with tumour specific pathway experts to agree minimum tumour specific content
- seek permission to share existing HWBE content across LCA member organisations from those who have already developed content that meets the agreed standard
- agree whether to take forward economic cost analysis of HWBEs with agreed tumour groups and/or Trusts.

This paper sets out to answer the first two points, and will provide the basis for working with the tumour pathway groups in order to answer point three. The final two bullet points will be answered in separate pieces of work.

3 Summary of Evidence for Health and Well-Being Events

- Research in long term condition management has shown that group-delivered interventions improve self-efficacy and reduce symptoms.
- The use of volunteers/expert patients is pivotal to the successful running of such events.
- People are willing to discuss issues perceived as sensitive in group settings with the same level of satisfaction reported as experienced in one-to-one care.
- The peer support and discussion found in group events is highly beneficial.
- Group sessions increase health literacy and enable the person to participate in their own health decision making. High levels of health literacy are associated with lower levels of post-treatment anxiety and depression.
- HWBEs provide not only information, but also a forum in which to explore and discuss it. This process helps to make the information more useful to the person.
- Group delivery is fundamentally more cost effective than other models of aftercare, because larger numbers of people are reached in a condensed time period.
- Other styles of group-based information giving, such as events/clinics run over several weeks, and with a greater amount of professional involvement, are more resource intensive.

4 LCA Agreed Models

Following the mapping, taking into account the responses given about current practice as well as national piloting reports and the evidence cited above, the LCA Survivorship Pathway Group has agreed that:

- to be considered a health and well-being event, there should be a group component
- involvement of service users is strongly encouraged in at least one of a number of ways:
 - as co-designers
 - as co-facilitators
 - as speakers, focusing particularly on their experiences
 - as volunteers to support the smooth running of the event
- stand alone, one-to-one appointments to provide information can be used to complete HNAs and TS and are classed as an end of treatment consultations, not HWBEs.

The following models should be considered:

1. A large one-off, group event (more than 20 attendees) lasting around two hours which:
 - can be tumour specific or generic
 - includes a marketplace of additional information for attendees to gather further information on topics of their choice
 - has signposting for onward referral, e.g. for specialist rehabilitation or psychological support services available

- is either offered pre-treatment, or more usually at the end of treatment
 - could include an invitation for a 'plus one'.
2. A series of workshops with a rolling programme which:
- runs in smaller groups, e.g. fewer than 20 attendees, or in a lecture theatre format
 - includes stand-alone events focused on a specified set of topics, e.g. lymphoedema, breathlessness management, dealing with anxiety and worry
 - runs over a defined time period, on an on-going basis
 - provides workshops which people attend dependent on their individual needs, i.e. they may attend only one or several, depending on the topics
 - covers prevention and symptom management such as return to work or becoming physically active, as well as symptom management.
3. A set of workshops run over a defined period of time, with fewer than 20 attendees which:
- run over several weeks with attendance expected at all sessions
 - a more intense style of event
 - requires much higher staffing resource, and so is more suited to those who have a higher identified need for professional support in a particular area
 - covers a range of topics or may have a specific theme, e.g. anxiety management.

5 Minimum content

Health and well-being events should have a focus on participants staying as well as possible for as long as possible, and so support people to live as active and full a life as they wish. The following topics should be included in all HWBEs:

- physical activity
- diet
- anxiety and worry
- tumour specific content as appropriate dependent on the model being used
- information on smoking cessation and alcohol use(consider how this is provided, as it won't be relevant to all attendees).

6 Factors to consider

6.1 Practical considerations

- Time of the day:
 - travel time can impact on the cost of public transport
 - early start times may make attendance difficult, particularly if morning routines to manage consequences of treatment, such as incontinence, need to start several hours before leaving the house
 - the time of the day the event runs may dictate whether there is an expectation that, e.g. lunch will be provided as opposed to just tea and coffee
 - for people who may be returning to work, evening events may be preferable.

- What type of refreshments can be provided? Is there an opportunity to provide healthier options, for example fruit? This may impact on the overall running costs.
- What venue are you able to use? Is it accessible to those with limited mobility? Is there space for information stalls and refreshments?
- How can you make sure the 'right' people are invited to attend?
- Is attendance expected and offered as an integral part of the person's pathway?
- If you work in a tertiary centre, are you best placed to offer the event? Could you work with the units to make the events closer to home for people to attend and to increase the population for whom the event is relevant?
- Is there an existing event in community or sector organisations, to which people can be signposted?
- Can you offer a place to a friend or family member to attend too?
- How are you going to evaluate the event, to make sure that it meets the needs of the people who attended? Consider not just patient experience, but patient reported outcomes too.

6.2 Administrative considerations

- Making health and well-being events an expected attendance, in the same way as any other appointment, has been reported to increased attendance.
- Invitation letters signed by the lead consultant can make a difference.
- Include the programme for the event with the invitation letter.
- Make sure you know what local services are available to signpost to; offer these services a space in your marketplace (Appendix 2).
- Make time to debrief as a team after each event, in order to think about what went well and what could be improved for subsequent events.
- Has your Trust already negotiated with commissioners how these events should be run? Are there any specific content or running considerations as a result?

6.3 Cost considerations

- Do you need to think about funding for the set-up of these events? How will you pay for refreshments, any equipment you need and the staff time to organise and run them?
- Have you discussed how you can register attendance at the events? Can they be coded as an out-patient attendance?
- Make sure you include cost impact within any evaluation you do, e.g. how much it cost to run. Can you show a reduction in admissions, CNS telephone contact time, or GP attendances as a result, for example?

7 Helpful Tools

- Example of administration checklist ([Appendix 1](#))
- <http://www.macmillan.org.uk/GetInvolved/Volunteer/CancerVoices/GettingStarted.aspx>
- Interactive keypads to get 'live' feedback, and gain audience participation in presentations

Appendix 1: Example Action Plan from The Hillingdon Hospital

Health and Well-Being Event: ACTION PLAN

Specialty:

Venue:

Date: W/b

	Activity	Responsible Person	Complete By:	Send To	Received	Actioned
1	Identify a suitable date from the options provided	Team		Lead		
2	Identify suitable patients with the criteria already provided			Lead		
3	Decide programme of presentations/speakers and arrange for external speakers to be booked					
4	Use or amend to suit existing invitation letter and booklet					
5	Submit patient list with full address demographics including telephone numbers			Lead		
6	Submit completed booklet and invitation letter			Lead		
7	Mail merge for invitation letters and posted					
8	Collation of acceptances/refusals					
9	Second tranche invitations sent out if required					
10	Evaluation forms (distributed at event)					
11	Analysis of evaluation forms	Team				

Amended with permission from The Hillingdon Hospitals NHS Foundation Trust

Appendix 2: Marketplace Stallholders to Consider

This is intended to act as a prompt, and is not an exhaustive or mandatory list.

Alcohol support services e.g. Al-Anon

Citizens Advice Bureaux

Complementary therapy services

Exercise on referral providers

Local hospices

Local childcare nurseries

Local patient support groups

Local smoking cessation support teams

Local third sector providers, e.g. Maggie's, The Haven, Paul's Cancer Support, Look Good, Feel Better

Local well-being groups providing, e.g. mindfulness or Pilates

Return to work support services