

Health and Wellbeing Events –

Hints & Tips (September 2016)

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Introduction

Health and Wellbeing events are one of the 4 elements of The Recovery Package along with a Holistic Needs Assessment and care plan, a Treatment Summary and a Cancer Care Review.

The purpose of the Health and Wellbeing event is to act as an education and support event to help patients move on after treatment and assist with the emotional impact of this transition. It aims to ensure people feel well supported during this period of transition between ending treatment and findings their “new normal” and where appropriate, to prepare the person for the transition to supported self-management.

According to Macmillan (1), the event should include advice on the relevant consequences of treatment and the recognition of issues, as well as details of who to contact. It should also provide information and support about work and finance, healthy lifestyles and physical activity.

The purpose of this document is to share the learnings from a 12 month project undertaken as part of the Colorectal Pathway Board with aim of improving services for patients living with and beyond colorectal cancer and funded by the Macmillan Living with and Beyond Cancer Innovation Fund. From a colorectal pathway perspective 8 of the 11 trusts have now run Health and Wellbeing events.

Planning the events

Format and tumour groups

The format of the event needs to be decided upon. The following questions need to be answered:

- 1) Who is the event for? E.g. single tumour group, 2/3 tumour groups with some similarities, or any tumour group
- 2) How long will the event last for? E.g. single session 1 day / 0.5 day vs programme of talks /workshops delivered on separate dates

Across the Colorectal Pathway Board different formats of event have been trialled from colorectal specific events, combining with one other tumour group or a generic tumour event, a one off half-day event or a programme of 4 workshops delivered over 4 consecutive weeks.

Provided the event has been planned with the needs of the patient group in mind and is available to all those who require it, then all formats of event can deliver the benefits required.

Which patients? How many patients?

For colorectal patients, the event needs to be available to all patients who have been treated with curative intent and may also be appropriate for some palliative patients. Careful consideration needs to be given as to whom the patient population is that should be attending the event to make sure it is appropriate for as many people as possible.

When deciding how many people to invite it needs to be weighed up against how frequently these types of events will be delivered. It should be made available to all those that the event is appropriate. Examples from the colorectal pathway board for colorectal only events suggest that running the events between 2 and 4 times a year means that between approximately 30 and 70 patients are identified and invited per event. This will obviously depend on number of resections performed and will vary from trust to trust and potentially over time.

When in follow-up pathway

The Manchester Cancer Colorectal Pathway Board agreed position is that patients should have access to a H&WB event within the first year after primary treatment. The optimal time is probably for this to be around 3-6 months.

Where to hold the event?

The location of the event needs to be appropriate for attendees and people delivering the session to travel to and with sufficient parking. The premises need to be suitable for holding the intended event e.g. right size for number of attendees, somewhere to hold a market place for information stalls, break out rooms and / or AV equipment to deliver presentations. The cost of the venue for hiring and food also needs to be factored in. Hospital premises can be cost effective if there is an appropriate venue. This will also make it easy for hospital staff who are involved in the running / presenting of the event to attend. Some trusts have negotiated great packages with local hotels.

Community facilities could also be considered such as leisure centres (especially as there is an increase in such facilities offering Macmillan exercise group) or community halls.

Agenda

Once the format of the event has been decided the agenda needs to be set. It is probably most appropriate for there to be a period of time dedicated to specific presentations / talks from health care professionals and a patient stories, along with some time for individuals to get information from a range of information stalls, relevant to their needs. Some time to allow attendees to meet with each other also works well and gives these individuals an opportunity to build their own support networks.

Examples of presentations given at some of the colorectal events are:

- Introduction to the Health and wellbeing events as part of the recovery package and follow-up pathways
- Bowel awareness (including signs and symptoms, when to get back in touch, late effects)
- Diet and Nutrition
- Fatigue and Psychological awareness
- Exercise and physical activity
- Patient Experience of Living With and Beyond Colorectal Cancer

If the event is to be a generic event, these can be tailored accordingly. The information may be given in a more generalised way and then the attendees directed to the information stalls to get more specific information as required. Or a particular cohort e.g. colorectal patients and diet advice, could be given a specific talk at the end of the presentations when the others have gone to the market place or there could be break-out rooms available.

Examples of information stalls invited to colorectal market places include:

- Beating Bowel Cancer
- Benefits Advisor
- Colorectal Support Group
- Continence services
- Dietician
- Healthy Minds
- Hospices
- Local Cancer Support Centres
- Macmillan 1-1 Support
- Macmillan Information Centre and Macmillan Connexions
- Macmillan Solutions
- Manchester Giants / Active (or other appropriate exercise group)
- Neil Cliffe Centre
- Relate
- Smoking cessation

- Stoma Care
- Work Adviser

- Others e.g. Healthcare professionals (CNS', Pelvic Floor, Radiographer), any of the presenters could also have a stand

The information provided at the event will be dependent on the type and format of event being given. This is not a definitive list but more a list of examples for consideration. It may be appropriate to have a lot of the information available e.g. via the Macmillan Information Centre stand rather than having individual stands which all require manning. There needs to be enough time for the patients to get around the market place and find it useful without feeling overwhelmed.

Setting up the events

Inviting attendees and finalising numbers

Patients should be identified by the CNS'. The patients should have been made aware about the H&WB event before they receive an invite. This could be done pre-operatively or post-operatively and may be verbal or via an information leaflet or poster at the hospital or in the community.

Patients need to understand that the H&WB event not an optional extra but more an integral part of their planned follow-up. Inviting patients using a format similar to a formal clinic letter can help to achieve this. An information leaflet highlighting the agenda and what is expected (e.g. this is a group event rather than a 1 to 1 session could also be sent out with the invite. The patients could be given the option to invite a companion if considered appropriate.

It is also important to ensure that patients confirm their attendance at the event or if can't attend get an option to attend a subsequent event as appropriate event. Whoever is responsible for inviting patients e.g. CNS secretary, specific Health and Wellbeing event co-ordinator, Macmillan Information officer, patient experience lead, if possible should follow-up with invitees to encourage attendance if no response has been received.

It is also important to have a good idea of how many will be attending to ensure catering requirements can be confirmed.

An example of an invite letter, which could be added to an automated letter system, is attached below:

MainRecipient
MainRecipientAddressLine1
MainRecipientAddressLine2
MainRecipientAddressLine3
MainRecipientAddressLine4
MainRecipientPostCode

Hospital No: PatientFACILNumber
NHS No: PatientNHSNumber

Date: CurrentDate
User ID: UserID

Dear

I write to confirm that an appointment has been made for you:

On: **ApptDate at ApptTime**
Clinic: **Health and Well-Being Clinic**

On arrival please report to the **xxx Building**. This is next to **Entrance X, Hospital, Address**.

Note: - There is visitor car parking close by – please bring the parking ticket with you and we will replace it with an exit ticket for free parking.

What is the Health and Well-being Clinic?

- ❖ The Health and Well-being Clinic is part of your cancer follow-up programme.
- ❖ The Clinic is a one-off group event. It helps people affected by cancer and carers to move from treatment of their cancer to living well beyond cancer.

What happens at the Health and Well-being Clinic?

- ❖ There will be talks from one of the Consultant Surgeons and on eating well, being more active and 'life after cancer' (psychologist and patient 'stories').
- ❖ There will also be a range of Information Stalls and professionals available when you arrive and at the end of the Clinic – for you to ask questions, pick up information and to find out more about local activities and support groups.

You are welcome to bring a friend or carer with you. Tea / coffee and a light lunch will be provided.

It is important you keep this appointment.

- ❖ **Please telephone 0000 000 0000 or email xxx@nhs.net to confirm you will be attending and if you are bringing someone with you.** Please also let us know if you have any specific needs, e.g.: diet.
- ❖ If you are not able to attend for any reason, please contact us on the same telephone number / email address to let us know. We will then make sure a new appointment is booked for you to come to the next Health and Well-being Clinic.

If you have any questions about the Health and Well-being Clinic, please get in touch.

Yours Sincerely

Colorectal Team

Inviting presenters and market stall holders

It is important that anyone contributing to the event from a professional perspective understands the purpose of the H&WB event so they can ensure the information they provide is most relevant. If tumour specific events are being run, they may be run on an e.g. 6 monthly basis but it is conceivable that presenters and information stall holders will be expected to attend multiple tumour group events more frequently. Similarly if it is a generic event then it may run more frequently than a specific event e.g. bimonthly, so regular attendance from presenters and stall holders is required and shouldn't be underestimated.

Presenters and stall holders should understand the huge value they are offering to cancer patients by getting involved with the H&WB event as the events are not possible without them. If a pool of people supporting the event could be identified then this would be beneficial.

Inviting contributors well in advance or providing them with a list of dates upfront and getting buy-in should help to ensure that the events can be supported. Also informing the contributors of the agenda and how long they are required for is important. Understanding that there are presentations as well as information stalls will help to make sure that everyone is informed. Overall though, it is vital to make the contributor's feel as involved as possible as the event needs them to be successful.

Catering

Some catering is likely required for all types of events. The cost of the catering should be understood upfront as may dictate when in the day the event will be held dependent on budget. Providing catering is about more than just providing refreshments. It gives the attendees an opportunity to talk to other people who are in a similar position to themselves and on a similar journey. It gives them an opportunity to network, ask questions to each other (and then seek answers from the H&WB event) and to form their own support groups. People may encourage each other to sign up to additional support groups or services on the day, knowing a friendly face is signing up too.

Holding the event in a morning (and providing tea / coffee and pastries for example), rather than over lunchtime could be a more cost-effective way of holding a H&WB event. A hot sit-down meal might be the most effective way to make attendees sit down and start socialising, but there could be budgetary implications.

Information bags

To ensure that patients leave the event with a minimum amount of information, it could be useful to provide all attendees with a partially pre-filled information bag. This might include bowel awareness information (including signs and symptoms, when to get back in touch, late effects, contact details), information on the Macmillan Centre and other charity leaflets. This bag can then be used to add more information to during the market place.

The local Macmillan Information Centre might be able to help with the provision of such bags and information.

On the day

On the day of the event it is useful to make sure that there are enough support people available to facilitate the attendees to ensure they get as much out of the event as possible and are pointed to the resources they may require. Such support people could be the CNS', presenters or information stall holders, representatives from the local colorectal (or other tumour group as appropriate) support group. Some attendees may feel unsure as to the purpose of the event or uncomfortable in the group environment so preparing up front for this will help the event to run more smoothly.

Patients often arrive early to such events so careful planning with regards to the start time for registration in relation to the first talk should be given. Patients could use this time before the talks to visit the information stands but they may not get as much from doing this had they waited until after the presentations. Keeping the time between registration and the start of any talks relatively short, may be a preferable option, or signposting to just one or 2 information stands e.g. Macmillan could be a solution.

If a presentation section is being held prior to a marketplace, it can work well to let the information stall holders briefly introduce themselves to the patients. By simply saying their name, the stand they are representing and why someone should visit them can help to engage the patients and make them think about what is relevant to them and what information they could do with. It further helps the stall holders to feel involved.

Feedback questionnaire

It is important to get feedback from the patients as to their experience of the event. It might be easiest to do this on the day by providing (in the information bags?) all attendees with a questionnaire to complete and hand in before they leave.

An example of a questionnaire that has been developed for use by the Colorectal CNS' is shown below. The intention is that the questions are all one sheet to make it simple to complete. Not all the questions from section B might be useful so these can be selected dependent on the evaluation required or further questions could be added.

COLORECTAL HEALTH AND WELLBEING CLINIC EVALUATION FORM

Your feedback is valuable! Please complete sections A-D

A. Are you the person affected by cancer or a friend/relative/carer ?

B. Please circle an appropriate response from 4 to 1 for each statement below:

	Strongly Agree (Yes)	Agree	Disagree	Strongly Disagree (No)	Additional Comments
Before I came today I understood that this event was part of my bowel cancer follow-up	4	3	2	1	
The timing of the event in relation to my cancer surgery / treatment and follow-up journey was appropriate	4	3	2	1	
The speakers were good	4	3	2	1	
I know what signs & symptoms to look out for that suggest the cancer may be coming back	4	3	2	1	
I feel confident about getting in touch with my cancer doctor/nurse or GP at any time if I am worried my cancer may be coming back	4	3	2	1	
I know how to get in touch with my cancer doctor/nurse if I am worried my cancer may be coming back	4	3	2	1	
There was a good variety of stalls	4	3	2	1	
The event has made me more aware of the different information and support options available	4	3	2	1	
After today I feel more confident about looking after my health & wellbeing	4	3	2	1	
I found it useful to meet other colorectal patients and carers	4	3	2	1	
Overall, I found today's event useful and informative	4	3	2	1	

C. Is there anything you will change (do differently) as a result of today's event?

D. Please use this space to give us any other feedback or suggestions on how we could improve future Health and Wellbeing Clinics/Events.

Was the start-time and duration of the event acceptable?

Feedback from presenters and stall holders

It is also valuable to get feedback from the presenters and stall holders to get another perspective on how the event went and to also consider what improvements could be made in the future. This could be done on the day or emailed out afterwards depending on relations. Useful questions could include:

1. Do you feel you have had sufficient background information about the Health and Well-being Events, their purpose and your role?

Yes

No

Don't know

If not, what information would be helpful?

2. What do you feel about the Health and Well-being Event?

Positive

Negative

Indifferent

Comments:-

3. The programme included time for you to introduce yourself and the information you have at your stall – do you think this was helpful?

Helpful

Not Helpful

Indifferent

Comments:-

4. Is there anything else you feel we could do to encourage patients/carers to visit your stall?

Comments:-

5. Have you found any benefits of attending the Health and Well-being Events? Eg: dedicated and focused time for patients/carers to contact you.

Comments:-

6. Are there any other changes you would like to see made to the Health and Well-being Events in the future, eg: programme content and timings etc?

Comments:-

Any additional comments:-

Many thanks for your help with this!

After the event

After the event, it is useful to take the time to reflect on how the H&WB event went and what could be done differently next time to improve it. It is important to review constructively the feedback from attendees, contributors as well as your own opinion to determine which changes should be made for any future events. It is also worthwhile sharing the feedback wider within the trust to ensure there is visibility of the event and an understanding of the value added. This will be important to ensure sustainability and continued funding of such events.

Also take the opportunity to thank contributors for their efforts and get their feedback if that hasn't already happened. Some contributors might appreciate a top level overview of any patient feedback to understand the value of the event.

The momentum from the event should be built upon, so the date for the next event should be planned in promptly.

References

Sharing best practice: Health and Wellbeing Events, Mac Voice – Summer 2016

<http://www.macmillan.org.uk/aboutus/healthandsocialcareprofessionals/newsandupdates/macvoice/summer2016/mac-voice-summer-2016.aspx>