

Patient Privacy Notice

Collaborative Thinking Ahead Programme

For patients and family members living with incurable cancer across Harrogate, Leeds, and Calderdale & Huddersfield

Introduction:

Thinking Ahead is a Health and Wellbeing Programme for patients living with incurable cancer, who may or may not be receiving treatment, as well as their family members. The course was devised in Harrogate in 2018 and has been delivered in Calderdale and Huddersfield and Leeds for the last 18 months. This course is a collaborative Thinking Ahead course between the three hospital Trusts, being run virtually over seven weeks on Microsoft Teams. This means that patients from all three districts are invited to join and that staff from all three areas will be taking part in presenting on the course.

What is the purpose of the Thinking Ahead Course?

- To help keep patients as well as possible for as long as possible.
- To encourage living life to the full in a supported, self-managed way.
- To offer support to family members.
- To give advice on local services and how to access them when needed.
- To allow an opportunity to consider future planning towards the end of life.
- To give an opportunity to meet key people who may be able to help in the future.
- To offer time for questions and concerns.

Why are you doing this?

We are running this programme as a collaborative online course in response to the Coronavirus pandemic and to pool staff resources and expertise across the Trusts. Running an online course allows patients and family members to join from across the geographical area, from the comfort of their own homes.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you decide to take part you will be given this privacy notice to keep. We will ask you to sign a consent form, which includes your consent to join a group video appointment with other patients and family members from the three Trusts. If you decide to take part, you are still free to withdraw at any time. You won't have to give us any specific reason for withdrawing. If you decide not to take part, or change your mind and withdraw, it won't affect the standard of care you receive.

What will happen to me if I take part?

You will be invited to join seven online sessions via Microsoft Teams. These will be in groups with other patients and family members and will cover different

topics such as diet, managing fatigue, hospice services, decisions and future planning, benefits and travel. Everyone joining the course will be issued with this privacy notice to keep and asked to complete a consent form.

What will happen to my data?

None of your clinical information will be shared with staff from other hospital Trusts than your own. Only your name, email address and phone number will be shared with the host Trust (i.e. the Trust which manages the bookings and sends out a booking invite).

What will the host Trust do with the data?

The host Trust will store your contact details for the duration of the course only and these will be deleted once the course has ended. Your contact details will only be used for the purpose of sending out booking appointments and course information e.g. handouts/reading material. Your data will not be used for any other purpose.

What happens to the data once the host Trust have finished with it?

Your contact details will be deleted by the host Trust once the course has finished. Only your own hospital Trust will have access to your clinical information.

Will information about me be kept confidential?

Your personal information will be kept confidential and your data will be stored in line with the Data Protection Act 2018, using appropriate security. You can choose how your name is displayed in the group video sessions, and you have the option not to turn on your camera and microphone.

Contact names and numbers

If you need any further information, please do not hesitate to contact the Thinking Ahead Course facilitators for your area:

Calderdale and Huddersfield patients – contact Helen Jones and Mandy Davies, Macmillan Information & Support Service on 01484 343614, 01422 222709 or email cancer.information@nhs.net.

Harrogate patients – Palliative & End of Life Administration Team (Rebecca Peacock) or Charlotte Rock (Macmillan Lead Nurse for Palliative and End of Life Care), Fysche Hall Clinic, Iles Lane, Knaresborough, HG5 8DY. Tel: 01423 553464 or email: palliativecareteam@nhs.net

Leeds Patients – For any queries/referral for initial assessment contact the Enhanced Supportive Care Service CNS, Lydia Skertchly on 0113 2064563 or email leedsth-tr.esc@nhs.net

Can I opt out of taking part in the Thinking Ahead Course?

Yes, you can opt out of doing this programme at any point. You will need to contact the staff members listed above to do this. You can also contact them if you have any questions about consent and use of your personal data.