Privacy Notice for the Thinking Ahead Programme

For people living with incurable cancer and/or their family members across Harrogate, Calderdale & Huddersfield, Leeds and Mid Yorkshire NHS Hospital Trust

Introduction*:*
Thinking Ahead is a Health and Wellbeing Education Programme for patients living with incurable cancer, who may or may not be receiving treatment, as well as their family members/carers. The course was devised in Harrogate and District NHS Foundation Trust in 2018 and has been delivered in Calderdale and Huddersfield NHS Foundation Trust since 2019 and Leeds Teaching Hospitals NHS Trust since 2020. Since 2021, these three trusts have run a collaborative virtual Thinking Ahead Programme for seven weeks on Microsoft Teams, for patients and family members across the three trusts. From 2024, Mid Yorkshire Teaching NHS Trust also joined the collaboration. This means that patients and family members from all four districts are invited to join and that staff from all four areas take 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 is this course running?
This programme supports people's quality of life as they live with incurable cancer. A collaborative online course was set up in response to the Coronavirus

pandemic and to pool staff resources and expertise across the Trusts/areas. 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 four 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, plus an optional introductory session the week before the course begins. The introductory session is to give people the chance to meet others on the course and for people to share their stories, if they would like to. The weekly sessions 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 managing uncertainty. 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. The host Trust is the hospital Trust which manages the bookings and sends out booking invites, as well as any follow up information after the weekly sessions

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 30 days after 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:

Harrogate: Contact the Macmillan Cancer Information and Support Service – 01423 557317 or email hdft.cancerinformation@nhs.net

Calderdale and Huddersfield: Contact the Macmillan Information & Support Service on 01484 343614, 01422 222709 or email cancer.information@nhs.net

Leeds: Contact your Specialist Cancer Nurse in Leeds Teaching Hospital Trust or email the Macmillan Information Centre on the Bexley Wing – leedsth-tr.cancersupport@nhs.net

Mid Yorkshire: Contact the Macmillan Cancer Support Centre on 01924 546072 or 01924 512204 or email midyorks.macmillan.infocentre@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.