



Information Needs of Cancer Patients and Caregivers in North Hampshire



A workshop
summary report

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Introduction

On 30th April 2024, Wessex Cancer Alliance, in partnership with Cancer Services Partnership, held an event in Basingstoke on the information needs of cancer patients. Around 35 people with lived experience attended the event, both patients and caregivers, and shared their views in a series of round table conversations. These were divided into parts of a 'cancer journey':

- **From diagnosis of cancer to when treatment starts**
- **During treatment**
- **Immediately after treatment**
- **Living with or beyond cancer**

Participants were able to share their experiences of receiving information, both good and bad, and discuss what could be done to improve the effectiveness of information giving. They were asked to consider information about their clinical care, information to support their general wellbeing (including diet, exercise and psychological support) and information for their family and caregivers.

The workshop was organised in response to the National Cancer Patient Experience Survey (2022) which revealed variations in understanding of diagnosis, treatment, short and longer-term side effects and symptoms of cancer recurrence. The survey also identified low awareness of support available outside hospital – for example from charities or community organisations.



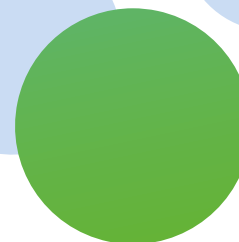
Key Findings

- Information needs to be personalised to patients and caregivers needs and circumstances
- People sometimes felt 'overwhelmed' by the amount of information they were given and struggled to access the information they did need as a result
- Some people wanted to know everything about their cancer, their treatment, test results, medications, prognosis etc and others said they only wanted to know what they needed to get through treatment.
- People sometimes found it difficult to understand information particularly where there was technical language, inconsistent information given by different people, jargon and abbreviations. People don't always understand cancer terms and what they might mean to them e.g. neutropenic and fatigue.
- Patients and caregivers need to receive information both face to face and written down, through a range of channels and in different formats, including languages, to meet their diverse needs
- People found it frustrating that there was no consistent way to share information across different people and teams involved in their care, including with GPs
- Several people talked about wanting a comprehensive 'health book' record for their cancer journey, in their preferred format, that is accessible to clinicians and caregivers (assuming there is consent)
- People felt there was a lack of wellbeing information and support given throughout for both patients and caregivers, and signposting to community-based support was inconsistent for different people and different cancers. Men in particular seemed to be rarely signposted to community-based support finding this 'by accident'
- Caregivers have their own needs and the burden of getting information and support for them often falls on the patient
- People don't necessarily know what to expect and won't always know what questions to ask - a patient won't know what they don't know! They may also need encouragement to ask for help.



Gaps in information and support

- More common cancers and treatment types have better information and support available. Breast cancer patients talked about being signposted to support but this was not the experience of people with other common cancers, including prostate and bowel. People with rarer cancers found it even more difficult to get information and support.
- There is not consistent information and support across the whole North Hampshire area.
- A gap in information and support for wider families and particularly the patient's children was identified.



Other general feedback

- Patients and caregivers are frustrated that NHS IT systems don't talk to each other so there isn't easy, consistent access to all their medical records
- NHS admin processes can be very wasteful. There is still an over-reliance on letters and the post when there are now more efficient ways of doing things.
- Right by You and other cancer coordination roles were praised.

Detailed Feedback

From diagnosis to starting treatment

Clinical Information

Clear verbal and written information, including in different languages and formats, is key to helping people understand their cancer diagnosis, what will happen, how they can prepare for treatment and what support is available to them.

The appointment invitation should clearly advise that people can be accompanied by a relative, caregiver or support worker.

At the appointment, the patient should be told what the diagnosis means for them and their family, as well as give clarity about wider family risk. It needs to be given in a straightforward way, so people understand this, explaining terminology for people who are hearing it for the first time. This information should be reiterated in a written format and provided via the person's preferred channel, including via the NHS app or email.

Good information and evidence about outcomes to make informed treatment choices gives people a sense of control over their lives. This includes information about short and long-term side effects, as well as whether no treatment is an option. Patients shouldn't need to do their own research.

Both patients and caregivers alike want to understand the treatment journey ahead of them, how it will make them feel physically and emotionally. Patients would find it helpful if care teams could communicate this to their caregivers directly.

Very practical information, for example, about what to wear to diagnostic or treatment appointments, contact cards and whether to have an overnight bag ready, would be useful too.

Effective, consistent communication and coordination of care across the different teams and organisations is especially important to patients and caregivers.

“
Treatment plans should be codeveloped to give me back some control of my life.
”



Wellbeing

Appropriate booklets and information should back up conversations, not replace them, remembering people access information differently at various times. 'Check-ins' for both patients and their caregivers, with either primary or secondary care, whilst waiting for treatment would be helpful.

Reliable wellbeing information should be 'drip fed' or given at the 'right time' rather than given all at once as that can be overwhelming. It needs to cover all elements of wellbeing - nutrition, emotional support, physical, peer support etc.

“

Is it appropriate to give a Macmillan leaflet with a lady on the front with no hair?

This made me cry. I was just diagnosed.

”

During treatment

Clinical Information

There was a call to remember that patients are people, and not their disease. Discuss with them how much information they want, when and how to provide it. A suggestion was to create a personal statement of care.

It is important to have clear, complete written information, including test results, held in one place that is accessible to patients and clinicians, and caregivers with consent. This should be provided using one 'portable' channel, e.g. on 'My Medical Record' or one App, if that is preferred by the person.

Someone suggested a checklist and/or FAQs (Frequently Asked Questions) to make sure that all relevant information has been shared with patients and caregivers. Another suggestion was to have a tool to manage medication, what must be taken and when, and what is optional but there to help manage side effects (such as nausea). During chemotherapy can be a suitable time to give information and answer questions, as well as have someone accompany patients, including in case there is an allergic reaction.

Providing access to Wi-Fi or having a mobile signal helps people communicate with the 'outside world' during treatments.

Some people would like to be able to record appointment conversations so they can listen back to understand better later. "Chemo brain" means it is hard to retain and recall information.

People want information about:

- how the process will work for the individual
- a plan of appointments, what they are for, and if cancelled, an explanation as to why (as this can cause unnecessary worry)
- support with travel, finances and other practicalities, e.g. radar keys, disabled parking badge, benefits and rights, returning to work
- contact details of who to contact with questions
- managing pain, including holistically and the possibility of stopping treatments if they need to
- short and long-term side effects - what is and isn't normal for a specific treatment
- infection risk
- dentistry
- clinical trials and new treatments as they come onstream (updating patients who may already be on treatment)
- holistic well-being advice, including signposting to national charities, community based and peer support, as well as the Cancer Care Map
- support for caregivers and loved ones during this time, and information about how they can help the patient

In terms of side effects, it is important how this is conveyed. Explain what terms like 'fatigue' mean. Information about the cold cap was thought to be good but telling people only 10% of people lose their hair makes the person feel worse when it happens to them. Someone said they would have liked to have known their hair may not grow back to prepare themselves. People would like more information about the side effects from radiotherapy.

It is always important to recognise people's privacy when asking personal questions and curtained cubicles in wards are not private spaces for difficult conversations.

Wellbeing

People shared positive feedback about community-based and peer support groups like Jane Scarth House, Wessex Cancer Support and the Pink Place. Macmillan Cancer Support information leaflets and the North Hampshire Radiotherapy Team, who gave clear information on diet and exercise during treatment, were also highlighted as good practice.

Personalised advice about diet and exercise to support recovery was deemed helpful, as was encouragement to take up emotional support and signposting to complementary therapies e.g. acupuncture for chemo side effects. People also found it useful to be told to make the most of times between treatments so they could still 'have a life'.

Immediately after treatment

Clinical Information

A 'debrief' conversation with a consultant immediately after an operation, giving a general view as to what happened and how it went gave welcome reassurance. Caregivers also need this. There is however, inconsistency across tumour sites, e.g. prostate cancer patients saying they wait up to six weeks for feedback.

This should be followed up with an end of treatment plan summary and a repetition of information about what will happen next, what to look out for, how to look after yourself, manage pain, sickness advice, risks, and any medication.

Patients want to be discharged with the right medication and equipment (syringes, PEG feeding etc.) and with instructions on how to use them (PEG feeding, self-administering daily injections, stomas). A caregiver described having to ring around different pharmacies trying to get medication after discharge and said, 'it shouldn't have to be a battle'.

Expected recovery milestones are helpful, as well as details about who to contact for help and how, e.g. email or call. A wallet contact card was suggested. Follow up appointments by phone are helpful so patients do not have to travel, as is a reminder to have someone with the patient to be a 'second pair of ears'.

Some said Right by You in Southampton is "fantastic". Others would like an overall care coordinator as you get different and occasionally inconsistent information from different clinicians in different teams/ trusts, and because CNSs are seen as very busy. Their support varies and there is a recognition that they are thinly spread so it can be difficult to get hold of them even when it would be helpful to run something unexpected past them.

Patients and caregivers would like clarity about when the GP takes over the overall management of their care.

After discharge patients and caregivers are left feeling vulnerable, not knowing what to expect. They want to know what life will be like after treatment, what follow up they can expect, and what to look out for in terms of recurrence. They would like information about how to talk to their wider family and friends.

“
There should be a proper handover to the GP, otherwise you are left in limbo.
”

Wellbeing

Patients and caregivers want personalised wellbeing information and support from trusted sources on issues like other parts of the pathway (listed above), plus information about other therapies that may aid recovery. Emotional support is still key at this point, as whilst there may be the relief of having had treatment, many patients and caregivers describe having just been 'holding it together' until treatment was over. They feel forgotten about at this stage.

Some suggested in person "Wellbeing" events for specific cancers covering psychological, physical and nutritional support. A good practice example was a one-off Roy Castle funded Lung Cancer Day attended by 46 people. It covered things like dietary, physio, breathing exercises etc., but also new developments in treatment and care. The feedback was positive. Macmillan Info Days in Southampton and their support packs were also mentioned.

Other good practice cited that wasn't specific to cancer was being referred to a sports centre, or after knee surgery being provided with a video about the procedure and exercise instructions.

Living with and beyond cancer

Clinical Information

At this point, patients would like assurance as to the effectiveness of treatment (or otherwise) and to understand what 'being vigilant for the rest of life' means if this applies to them.

If palliative care is needed, there needs to be a careful introduction for patients and caregivers, but doctors do need to tell them, rather than them finding out directly from the palliative care team following a referral. A care package for these patients would be useful.

Patients, who do not need palliative care would like support and education to help them take responsibility for their own health. This could be through courses like the 'Moving Forward' or 'Hope' courses, but these are not universally offered.

Information and support still need to be holistic and delivered face to face as well as in other formats. It needs to cover practicalities of returning to life and work; benefits; home help, as well as medication and side effects, what to expect and how long may things last. Knowing who you can ask for what, especially in an emergency, with concerns about recurrence or how the disease will progress, would be also useful. Information about support for caregivers is also important.

There needs to be better links with the GP, with them being better educated about managing cancer patients longer-term. Cancer care reviews are not always done.

Wellbeing

Psychological support is still needed as people spoke of the fear of recurrence. As is support with diet and exercise about what to do, when. Having a summary sheet of support in the community would also be welcome.



My life is different after my cancer journey so I couldn't just go back to the life I had before. I needed to know my options for work, benefits, emotional support etc



Next steps

We will take the following actions:

- Share these findings with Lead Cancer Nurses at local Hospital Trusts, Wessex Cancer Alliance GPs, other doctors in hospitals and GPs, Cancer Care Coordinators, local charities and cancer support groups
- Pull together a working group to see what practical changes can be made in the short and medium term to improve information sharing with patients. Involve people with lived experience in this working group
- Pilot at least one project focused on improving clinical information and one on improving wellbeing information
- Report back to attendees and other interested people after 6 months and 12 months with the progress we have made
- Assess whether people with lived experience of cancer in other parts of Wessex would like to be involved in a similar exercise in their local area

Contact details

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