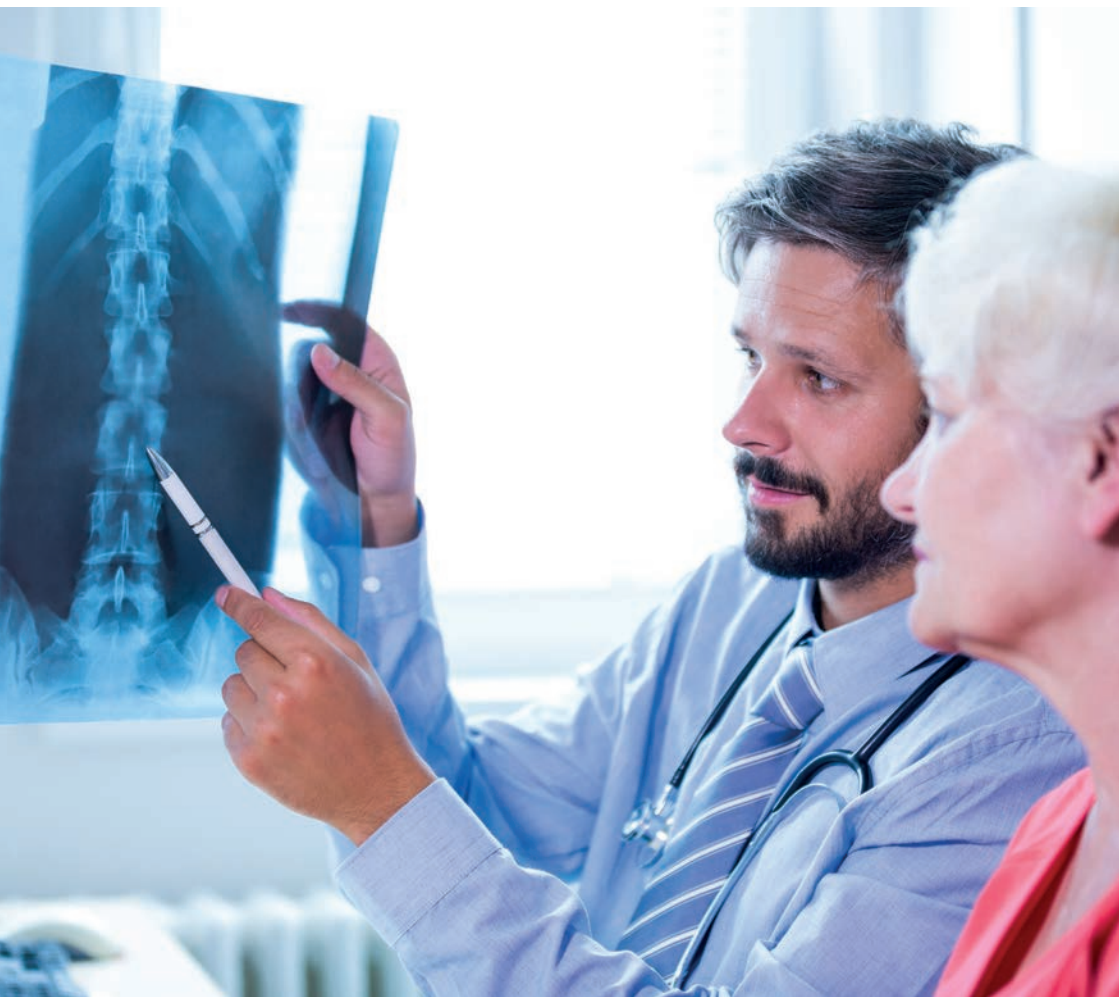


Supporting someone who has cancer and dementia: Advice for health professionals





Is dementia common in people with cancer?

At least 1 in 13 (7.5%) people aged 75+ with a diagnosis of cancer will also have a diagnosis of dementia as a comorbidity.

This is likely to under-estimate the prevalence, given dementia diagnosis rates are around 60-70%.

This leaflet provides practical advice to help you support someone with dementia through cancer treatment and care. It is based on research carried out by Leeds Beckett University that looked at the cancer treatment and care experiences of people with dementia.



Do people with comorbid cancer and dementia have different needs?

Yes. Having dementia alongside cancer brings problems with memory, reasoning and managing day-to-day living, creating additional or different needs to someone who has cancer alone.

People with cancer and dementia are more likely to have additional comorbidities, meaning they have increased likelihood of being more medically and socially complex to treat and care for than people with cancer alone.

Our research suggests that the approaches on the following pages can help oncology staff to make cancer treatment and care run more smoothly for someone with dementia.



Ask, record and communicate

Ask if the person has dementia or memory problems and record this clearly in their medical records.

It may not always be obvious during a consultation that a person has dementia so do not assume you will notice.

Family members accompanying a person may not feel able to share this information unless you ask. They may also assume you know the person has dementia.

Communicate that someone has dementia and share details of any special needs or things that will help to make their experiences of oncology services easier, with other members of the team who may need to know.



Use pictures and personalised written reminders

Having dementia may mean people are less able to retain information about their diagnosis and treatment options or decisions.

Carers also may struggle to understand and relay this to them later. Providing personalised information can be helpful, for example, diagrams of the tumour site and size, accompanied by short, written information.

Use simple, jargon free explanations and check understanding

Try to use language that is simple and free of medical jargon and terminology. A person with dementia or their family member supporter may not feel able to say they don't understand or to ask questions.

It is, therefore, important that you check their understanding and encourage them to say if anything isn't clear.



Informed decisions may need extra time

Having dementia can impact a person's ability to make decisions about cancer treatment. This does not mean people are not able to make informed decisions though, with the right support.

This involves presenting information simply, asking about the person's strengths and limitations, and considering how they may manage the requirements and side-effects that result from different treatments (e.g. lying still, tiredness or memory problems, dealing with a changed body or management of catheters etc).

Dealing with these circumstances may put an additional burden on a carer too. Therefore, people with dementia may need additional supports in place after cancer treatment to enable them and their family to manage.



Include the family/supporter without excluding the person with cancer and dementia

Families often play a vital role in supporting a person with dementia to attend hospital and manage cancer treatment.

Without excluding the person with dementia and with their permission, ensure their relative/friend is involved/included where appropriate.

For example, sending them duplicate copies of appointment and clinic letters, including them on bookings for patient transport and involving them in decision-making.

Make sure that information about aftercare, symptoms or managing things such as catheters is explained to both people.



Flexibility

Appointment flexibility such as longer appointment slots to support a slower pace or early/late appointment times can be extremely helpful to the person with dementia and their accompanying family member.

For example, getting out of the house for an early appointment may be difficult particularly if they rely on patient transport services, while some families may prefer an early appointment when car parks and waiting areas are generally quieter.

Consider if follow-up appointments could be conducted by telephone once treatment and aftercare is complete, if attending the hospital is stressful for the person with dementia.

Consistency

People with dementia can benefit from familiarity and seeing the same staff and using the same treatment rooms. Try to ensure this happens wherever possible when booking appointments.



A 'dementia friendly' physical environment

Hospitals can be frightening, confusing and difficult to navigate. Simple things can make a big difference to people with dementia.

Examples include:

- Clear pictorial and written signage to treatment rooms, toilets, waiting areas and the way out.
- Creating quieter waiting areas with items such as reminiscence books, jigsaws and other objects to help pass the time.
- Providing facilities to get drinks and snacks within waiting areas rather than people having to navigate their way to a canteen or shop.

The King's Fund has produced a useful guide to good hospital design for people with dementia.

kingsfund.org.uk/projects/enhancing-healing-environment



Think transport and arrival and departure arrangements

Arriving and departing from an outpatient appointment can be very stressful for a person with cancer and dementia and their relative/supporter.

Patient transport often collects people many hours before their appointment, can involve a long journey and then a long wait before and after an appointment, which is particularly tiring.

Car parking may be a long distance from the hospital entrance and if the relative/supporter drops the person with dementia at the door, there is a risk they may wander off while their carer parks the car.

Providing someone (e.g. volunteer, patient support staff) who can meet and greet at the door and sit with people who are waiting alone, or reserved parking spaces near the building, can make a difference.



Staff trained in dementia

Many oncology staff report that they do not feel they have had any, or adequate, dementia specific training.

Most hospitals have a dementia lead and a range of dementia training available, so ask what is available within your hospital. If there isn't anything suitable ask what can be provided for staff in your department.



Further advice and support

Dementia UK run a helpline that is staffed by trained Admiral Nurses. They specialise in care and support for people with dementia but can provide advice around supporting a person with dementia who has cancer.

Dementia UK free helpline: 0800 888 6678

9am-9pm Monday to Friday

9am-5pm Saturday and Sunday.

www.dementiauk.org/get-support/how-we-can-support-you

The Alzheimer's Society host a Dementia Connect support line where calls are charged at local rate.

Dementia Connect support line: 03300 947 400

9am-8pm Monday to Wednesday

9am-5pm Thursday and Friday

10am-4pm Sat and Sun.

www.alzheimers.org.uk/dementia-connect-support-line

They also have on-line forum called 'Dementia Talking Point' which has a section specifically dedicated to people affected by cancer and dementia. Carers report using it can be helpful to help them feel they are not alone.

Dementia Talking Point forum

forum.alzheimers.org.uk/forums/caring-for-a-person-with-dementia-and-cancer.81/

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If you would like more copies of this leaflet please scan the QR code to get to an electronic copy, or contact the Centre for Dementia Research, Leeds Beckett University.

