

# Supporting someone who has cancer and dementia or memory problems.



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## Supporting someone who has cancer and dementia

Having dementia alongside cancer can mean the person you are supporting may have additional or different needs to someone who has cancer alone. This leaflet provides practical advice based on research and tips to help you manage cancer treatment and care when supporting someone living with dementia.

**This leaflet is based on research carried out by Leeds Beckett University that looked at the cancer treatment and care experiences of people with dementia.**



## **Tell healthcare staff they have dementia**

Make sure all staff are aware that the person you support has dementia, as this may not be clearly recorded in their health records. The staff caring for them may not know or notice the person has dementia if you do not tell them. Do not assume this information has been passed on, for example from their GP or from one staff member to another.

It may also be helpful to explain how having dementia affects that person, so staff understand what additional needs they may have.

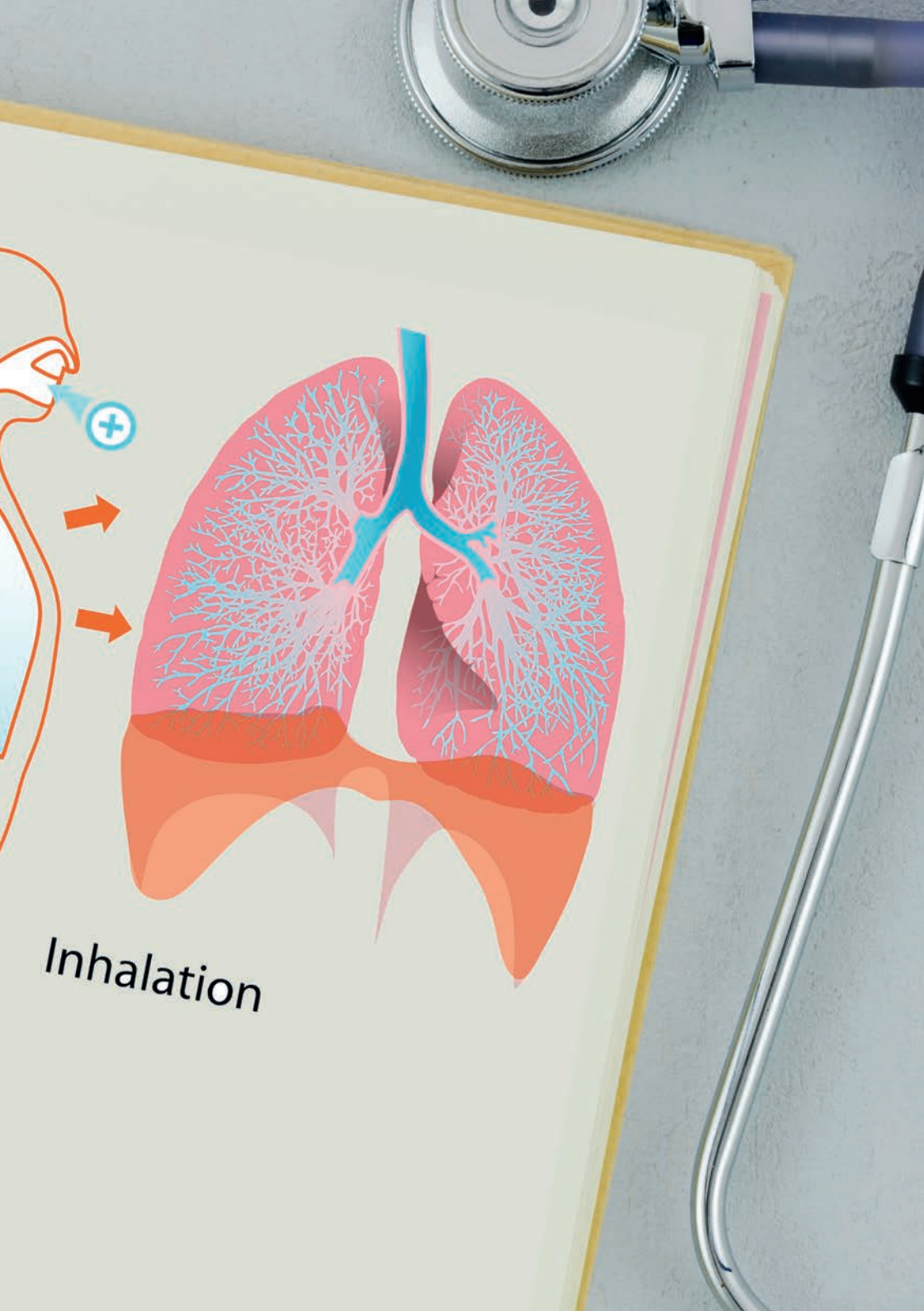


## **Prepare personal information**

Prepare information about any needs, likes or dislikes the person you support has (e.g. how to best communicate with them, things that help them to relax, things they like to talk about, how to tell if they are in pain or uncomfortable). This can help during any admissions or treatment. Documents such as the Alzheimer's Society's 'This is me' form can provide a useful template for this, or the hospital may have their own form you can fill in.

## **Ask if you don't understand anything**

Sometimes doctors, nurses and other healthcare staff might not explain things in a way that is easy to understand. Don't be afraid to say if you don't understand and to ask for things to be explained again or in a different way.



## Take information away

Ask for information to be provided about the person's cancer diagnosis and treatment options for you to take away and discuss. Pictures and personalised written information can help you to explain and recall key facts and may help you to explain them to the person you are supporting later.

## Take time to make informed decisions

When making decisions about cancer treatments there may be additional things to think about when supporting someone who also has dementia. Make sure you ask the doctor/nurse about how the person you support having dementia might impact the different treatment options. For example, some treatments may cause greater tiredness or forgetfulness, may require the person to visit the hospital daily for several weeks and to lie very still during treatment or may have after care consideration such as managing a catheter. Take the time you and the person you are supporting need to make the decision that is right for you.



## Support during and after treatment

Ask for things that will help support the person with cancer and dementia and you during and after treatment. For example, you could ask to visit the department where treatment will take place for a practice run and to become familiar with the environment. Most hospitals are able to offer things like a person's carer/supporter staying with them for as long as is possible in treatment rooms or playing their favourite music during treatment.

You should also ask for any support you may need at home to be arranged by the hospital e.g. district nurse visits or equipment.



## Flexibility

Don't be afraid to ask if the staff can be flexible with appointments and arrangements for getting to the hospital. For example, if getting out of the house for an early appointment will be difficult ask if they can provide a late morning/afternoon one. Sometimes it may be possible to have free parking or to conduct follow-up appointments by telephone once treatment and aftercare is complete.

## Consistency

People with dementia can benefit from seeing the same staff and using the same treatment rooms. Ask if this is possible when booking appointments.



## Family/friend inclusion

If the person you support needs help with managing treatment then make sure you make this clear to the hospital.

With the person's permission hospital staff can send copies of hospital letters to a carer/supporter to help manage appointments and information. They can ensure a carer/supporter is included on bookings for patient transport (this must be booked ahead of time otherwise an escort will not be allowed to travel). You can also ensure that information about the diagnosis, treatment, symptoms and aftercare is explained to you both.





## Where to get 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](http://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](http://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/](http://forum.alzheimers.org.uk/forums/caring-for-a-person-with-dementia-and-cancer.81/)





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.



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