

WE ARE
MACMILLAN.
CANCER SUPPORT

SUPPORTING CARERS OF PEOPLE WITH CANCER

Practical guidance for healthcare professionals



Wendy, living with cancer, and her daughter Sharon who cares for her

A carer is 'a person who gives unpaid support to someone with cancer who couldn't manage without this help'. Many carers don't see themselves as such, but rather as a partner, friend or relative of the person with cancer. You can help them recognise that they are also a carer, and may be eligible for support. This will help them to look after themselves, as well as the person with cancer.

Carers provide help with personal care, healthcare tasks, transport to hospital, shopping/collecting prescriptions, emotional support, housework and other tasks. The care they provide is vital but can have a big impact on them emotionally, physically and financially. Many carers struggle without help, which can lead to a crisis and even emergency hospital admissions. You can help by identifying cancer carers and signposting them to information, advice and support, as early as possible.

How to identify a cancer carer

- The carer may be a partner, family member or friend. They may not live with the person they care for, and may have other responsibilities such as work and dependent children.
- Cancer carers can be of any age, including under 18, but 22% are aged 45–44.
- 62% of cancer carers are female, but there are growing numbers of male carers.
- The carer could be the person who brings the person with cancer to hospital, visits them on the ward regularly, and/or accompanies them to appointments/treatment sessions.
- There may be more than one carer looking after the person with cancer, as friends and family members take on different tasks and roles.
- The carer may have been identified during the patient's assessment. You could check the patient's record – the person named as their next of kin may also be their carer.

'Ask the patient: who's at home, who do you get support from, who do you support?'

Healthcare professional

- If appropriate, you could ask the person with cancer if they have a friend or family member who is supporting them. Remember this can include young people under 18.
- Avoid asking the patient if they have a 'carer' or if someone is 'caring' for them - many people aren't familiar with this term and may think you mean a paid care worker.
- Cancer patients from Black and Minority Ethnic communities may be unfamiliar with the concept of being a 'carer', especially as the term may not exist in their language.
- If the patient does have someone looking after them, you could ask how this person is coping.
- Explain that **there is support available** for people who look after (care for) a relative or friend with cancer.
- If you're not able to find out from the patient if anyone is caring for them, you may need to identify their carer(s) yourself.
- Remember their carer may visit in the evenings due to work or other responsibilities at home.
- Their carer may ask you or other colleagues about the patient's condition/ treatment. They may also ask for advice about looking after them at home.
- If the cancer patient's family and friends don't speak English as a first language they may not approach you in this way. You may need to initiate conversations with the help of an interpreter – see your hospital's policy on this.

Talking to carers

- If you think someone may have taken on a caring role, you could ask them if they are 'looking after' the cancer patient. Avoid asking if they are 'caring' for the patient or if they are a 'carer'.
- You could ask them what they are doing to support the patient, and how it's affecting them.
- Explain that support is available and even if they don't need it now, it may be helpful in future.
- Some carers may not feel comfortable asking for, or being offered, support. You could reassure them that getting help for themselves can help them to continue in their caring role.



Remember that some people may not be able, or willing, to provide care for the person with cancer. It's important not to make assumptions about who may be a carer, and they shouldn't feel pressured into taking on the role.

Where to signpost cancer carers

Having identified that someone has taken on a caring role, you can signpost them quickly and easily to a range of support:

- Macmillan provides information, and practical and emotional support, for carers of people with cancer.



Carers can contact Macmillan free on **0808 808 00 00** Monday-Friday, 9am-8pm or visit [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

- Carers are entitled to a Carers Assessment. This is carried out by their local social services/social work department to identify their needs, and what support they may be entitled to. Your hospital should have a referral procedure, or ask a social worker how to do this. Always get the carer's permission to make the referral, or find out if they are able to self-refer. They can have an assessment of their needs and get support, even if the person with cancer doesn't want their own needs assessed.

- Support for young carers should be part of support for the whole family e.g. referral to the appropriate agencies. Young carers can be signposted to specific young carers services with their parents' permission.
- Your hospital may offer support for cancer carers, such as help with travel and parking costs. Contact your PALS department (England), Community Health Council (Wales) or Patient Advice and Support Service (Scotland).
- Other sources of support include:
 - Carers UK **carersuk.org** (expert advice and support for all the UK's carers),
 - Carers Trust **carers.org** (network of local support for carers),
 - Carers Direct **nhs.uk/carersdirect**
 - and **wales.nhs.uk/carers** (Wales) or **show.scot.nhs.uk** (Scotland).
- Organisations focussing on specific cancer types can also provide support for carers.
- Local support for cancer carers – find out local sources of support and write the contact details here for your reference, including:
 - a) Social Services/Social Work (to refer for a carer's assessment)

b) Local support available from Macmillan – **macmillan.org.uk/in-your-area**

c) Local carers centre and/or Crossroads respite service – **www.carers.org**



The earlier you can signpost the carer to support, the better. Their needs and situation will change with those of the person with cancer so check in with the carer(s) regularly to see if they need any additional information or support. Remember to document the carers details and action taken in the patient's nursing/medical notes and other relevant systems.

As a professional, you know cancer doesn't just affect the people you support physically. It can affect everything – their relationships, finances, work. You may feel that there aren't enough hours in the day to spend as long as you'd like with them, or to answer all their questions.

Macmillan can help, whether it's offering additional benefits advice, guidance on returning to work, or helping people make plans for their future. We can help you give them the support they need to feel more in control of their lives.

Visit [macmillan.org.uk/profs](https://www.macmillan.org.uk/profs) to find out more.

And let your patients know they can contact us free on **0808 808 00 00** (Monday to Friday, 8am – 9pm) if they need additional support.

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