

Having someone with you during your cancer appointments and treatment:

A GUIDE FOR YOUNG PEOPLE WITH CANCER

The coronavirus pandemic has affected every area of life, including cancer care, how this is organised and managed to keep patients safe while treatment continues. To help stop the spread of coronavirus (COVID-19), most hospitals have stopped or reduced the visiting. This means that some young people with cancer are having to have treatment and attend appointments on their own.

As we move into a new stage of the pandemic, we hope these restrictions can be reduced over time, it is helpful to look at what the NHS Wales guidance says: 'visiting should be with a clear purpose and agreement for visiting based on the best interests of the patient/ service user or the well-being of the visitor....People with long term conditions which necessitate increased length of stay in a healthcare setting or people with specific care and well-being needs that the visitor/carer actively contributes to, for example, feeding, supporting communication needs and supporting rehabilitation. The health and well-being of these patients may benefit from seeing appropriate visitors, as their length of stay is over many weeks. This should be documented in their care plan.'

In other words, visiting can happen where safe and in your best interest. In particular those in hospital for long stays can ask for this to be part of the care plan.

Teenage Cancer Trust and CLIC Sargent want all young people to have a #Hand2Hold - that's why we have campaigned to raise awareness of this, and why we've now produced this quick guide to help you get the best out of your hospital visit or stay when it's not possible to have someone with you.

And remember, if you ever have questions about your care, your appointments, or your treatment, it's always OK to ask your treatment team.

1. IT'S OK TO ASK TO HAVE SOMEONE WITH YOU

- The first thing to remember is that the NHS themselves have said that, having someone with you for your appointments and treatment should be made possible where it can.
- The NHS Wales guidance says: "face-to-face visiting needs to be agreed in advance" and visitors may be allowed to accompany patients to scheduled appointments where "the treatment is likely to provide the patient distress and the visitor can provide support". So the main message is that it's ok to ask about having someone with you if it's not been mentioned. You don't need to feel guilty or like you're asking too much of people.
- In November 2020, NHS Wales published guidance about how hospitals should make these visits possible. If you have been told that someone can come with you, it might be good for that person to read this before you go, so that they can be sure what they need to do and help the visit go smoothly and safely.

2. ASK FOR MORE INFORMATION IF YOU'RE TOLD YOU CAN'T HAVE SOMEONE WITH YOU

If you're told that you can't have someone with you during your treatment or appointments, you have the right to ask the staff to explain why this is, and what alternatives are available.



3. TELL SOMEONE WHY HAVING SOMEONE WITH YOU IS IMPORTANT

- Having someone with you is really important for many young people with cancer. This is your treatment, so your feelings and wishes should be considered as far as possible. If you want somebody there with you, you have every right to tell your treatment team.
- Here are some common reasons young people find having someone with them helpful. If they're true for you, it might be helpful to tell your care team:
 - "I've had an appointment on my own before, and I couldn't remember the information I was given because I get too stressed - my Mum / Dad / partner takes it in better than I do on my own, and take notes for me too."
 - "I'm really struggling at the moment and my mood has been low. Having my Mum / Dad / partner / friend with me helps me cope."
 - "I have a phobia of needles and having someone with me who I trust means I'll feel much calmer and you can get the job done more quickly."
 - "I'm too scared to do this on my own."

4. ASK IF THERE COULD BE REASONABLE ADJUSTMENTS MADE SO YOU CAN HAVE SOMEONE WITH YOU

- Some hospitals have options for testing parents, relatives or partners for coronavirus in advance so that it's safe for them to be there.
- There may also be options like having the appointment in a different area, or giving the other person Personal Protective Equipment (PPE) such as hospital grade masks and gloves to wear.
- It's ok to ask for this if you've been told initially that it's not possible for someone to come with you. Even if it doesn't end up being possible - it's your right to ask.

5. ASK IF YOUR APPOINTMENT COULD BE DONE REMOTELY

- If you are an outpatient (only going into the hospital for an appointment, rather than staying overnight), you might not need to be there in person all of the time. So you could ask if some appointments could be done remotely if you would prefer that.
- If this is possible it could mean you might be able to have someone there with you at home.

6. ASK IF YOU COULD HAVE SOMEONE WITH YOU ON A VIDEO/PHONE CALL

- In some circumstances, it might not be safe to have someone with you in person, and some appointments can't be done remotely.
- If this is the case for you, NHS Wales guidance says that hospitals should encourage and support 'virtual visits' where possible, which means someone could join your appointments by video or phone call. If this is something that you would like and is not offered to you, you can ask if a parent, partner or friend can video or call in.
- It might be helpful to:
 - Explain to your team that someone calling in will help you remember the information you often forget and questions you want to ask too
 - You can also explain that the person will give you reassurance when you're feeling scared
 - Check your phone or tablet is charged before your appointment to make sure the call doesn't cut out
 - Ask if the area where your appointment will be has a good phone signal and/or 4G or Wifi, as that could affect how much the person can hear. If it doesn't, you can ask if the appointment could be done in a part of the hospital that does get signal.
 - If the hospital is worried about protecting the privacy of hospital staff, let them know that you won't film, record or live stream the health professionals and if necessary, offer to sign something to say that the call is only for your personal support.

If you need more support in asking for someone to be with you, talk to your nurse, youth support coordinator, social worker or your GP. You can also talk to family and friends, or someone you trust.

And remember, it's always ok to ask for what you need during your cancer treatment. The people looking after you will always want to do everything they can to make you as comfortable as possible.