

## Virtual wards: what you need to know as an unpaid carer

## About this guide

"We have worked with Carers UK to develop this guide to help and support you to better understand virtual wards as an unpaid carer.

"Many of us have experienced caring for a family member or friend. This guide, in particular, looks at the things that matter to those who are starting out on their caring journey and about to provide care for the first time. However, it also provides a useful resource to existing carers who are about to experience a virtual ward for the first time. It features a checklist to help you ask the right questions and have the right information before the person you are caring for is placed on a virtual ward.

"The guide has been developed with the experiences of unpaid carers in mind. We have all experienced hospital discharge or support in the home. Although we have a great deal of experience of caring for people with different health conditions, we remember what it was like when we started caring or faced a new situation.

"Please do remember that if you are caring for someone, you do have the choice about whether or not to provide or continue providing care.

"We hope this guide will help you to understand more about virtual wards."

Dame Philippa Russell Anne Ward Ongley Linda Hughes Norman Phillips Laura Collins Amanda Threlfall





#### Answers to your questions and concerns

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#### What are virtual wards?

Virtual wards can be described as a service that helps patients to manage their care and health at home over the short term, with close monitoring by their care teams, rather than in hospital. Support may also be provided face to face by multi-disciplinary teams based in the area. Virtual wards enable more rapid discharge of patients from hospital, or help provide an alternative to admission to hospital in the first place. They are usually used to help with more concentrated care that typically might last from 1 to 14 days, supporting people who are aged over 65 and frail or living with certain conditions such as dementia, Chronic Obstructive Pulmonary Disease (COPD) or heart failure.

Evidence shows that virtual wards can improve outcomes for patients. However, they can also mean that families have to take on more intense care to support the person they care for at home, which can significantly increase their caring responsibilities.

Supporting someone at home who has been placed on a virtual ward may be preferable for some of us who are caring, because it could prevent hospital admission or enable quicker discharge. However, for other carers, it can be more of a challenge.

We know that better outcomes can be achieved for patients and carers if we understand what caring situations we face and are involved as part of the team by the healthcare professionals we meet. However, good practice is not always followed, so it's important to make sure you are knowledgeable and feel that you are making the right decisions – both for yourself, and the person you care for.

We have an explainer which provides more detail about what virtual wards are, here: carersuk.org/briefings/a-policy-briefing-regarding-virtual-wards/

We also have a carer leaflet that provides information if you are providing or about to provide care: carersuk.org/help-and-advice/guides-and-tools/looking-after-someone-guide/

You can also find out more information about virtual wards on the NHS England website: england.nhs.uk/virtual-wards/

"It's so important that you read this and follow this even if you are busy and have got a lot on. It can be really difficult knowing whether you are making the right decisions, but this checklist can help you to make sure that you have the right information, help you be treated as a partner in care and support your relative better. I've been caring for decades, and I've found this approach essential."

"Don't assume that things will happen, you need to ask, make sure you know, make the right choices for you and keep informed!"

#### I'm not sure what is meant by a virtual ward...

Virtual wards support patients to receive the acute (short-term) care, monitoring and treatment they need in their own home. They would otherwise be in hospital.

Usually, 1 to 14 days of support will be provided at home. Patients are monitored remotely using technology so that they can leave hospital sooner or as an alternative to being admitted to hospital.

It might be called something other than a virtual ward locally, such as a frailty virtual ward, Hospital at Home or an Acute Respiratory Infection virtual ward.

#### **I've read Carers UK's explainer** about virtual wards

#### How will I know what is going on?

You have a right to be involved in the care of the person you support. Health services have a responsibility to involve you (where appropriate) in the care of the person you are looking after if you are providing care. Let them know that you are the patient's unpaid carer and want to be involved. They can say 'no', but only if it is not appropriate, or the patient does not give consent (if they are able to).

Health services also have a responsibility to share information (verbally and in print) with you as a carer if you are providing unpaid care for the patient and your care is central to their health and wellbeing. They should also share information with you to protect your own health and wellbeing.

If the person you care for can't make decisions because they are ill or lack capacity, and you cannot get their consent, the law says that you must be acting in their best interests. Good care means that if you are caring for someone who cannot consent, making sure you are involved and have the right information is central to their wellbeing and health.

- I've asked to be involved
- I've asked for information to be shared with me, including medication, services, decisions and what is happening
- ☑ I've got the consent of the person I care for to have confidential information shared with me

# Will the virtual ward team know I'm someone's carer or that I'll be involved?

Not necessarily. It's important that you ask to be flagged as the patient's unpaid carer on their patient record. It's also a good idea to ask if your role providing unpaid care can be noted on your own GP record.

#### I've asked to be recorded as an unpaid carer on the patient record of the person I care for

"It's so important that you get consent if you can and get it recorded. It saves a lot of explaining."

"I'd always recommend that you get flagged as an unpaid carer on health records. I think it's going to become even more important over time."

#### How would I address any concerns I have about caring?

It's best to raise any questions or worries you have with the health providers and ensure that you are clear about your ability to care and whether you want to care. Be clear about the time you may or may not have available to care. For example, if you are working, or you have young children, you might not be able to provide 24-hour support. Also mention things you don't know how to do, like moving someone safely.

Local authorities have a responsibility to make sure that you have a choice about providing unpaid care, and that you are willing and able to care. You can ask for a rapid carer's assessment so that you have the opportunity of raising this. Decision makers should not be making assumptions about what you can do.

- The person in charge and making decisions has been clear with me about what they want my help with and where I might be needed
- I've told the person in charge about what I think I can/cannot do
- I've made a note of who I've discussed this with, what they do, and I've made a note of the date
- **I've got my link to my local carers' support organisation**
- **I've got Carers UK's information and advice to hand**

#### How will I be supported to coordinate their care?

Make sure that you are clear about what time you have to provide or coordinate care. You could make a list of all the relevant virtual ward contacts as well as what their role is so that you know what should be happening when and who is supposed to be delivering care.

Remember, you have a choice about whether you care or how much care you provide and this is your legal right. The virtual ward team must take this into account.

- I've made clear to the virtual ward team if I will or will not have trouble providing or coordinating care
- ☑ I've recorded a list of key contacts and their roles relating to the care of the person I care for

## How can I juggle my work with caring?

Don't forget you have a choice about how much care you provide. Check your employer's policies on flexible working – you might be able to sort things out with an informal chat with your manager, or you might want to make a formal request to work flexibly (you have the right to do this). Your employer might also have leave provisions. You have the right to take a short amount of time off in an emergency.

Check out your rights here:

carersuk.org/help-and-advice/work-and-career/your-rights-in-work/

- I've checked what my rights are as a working carer
- **I've asked about all the support mechanisms that are available**

# What happens if I'm not able to care at short notice or in an emergency?

We suggest making a contingency/emergency plan. Some local areas have processes for this in place and you can talk to the people providing care about doing this. Make sure you make a note of what they can provide. You can find advice about making an emergency plan, here: carersuk.org/help-and-advice/practical-support/creating-a-contingency-plan/

I've made an emergency plan in case I'm not able to care suddenly for whatever reason

### Will the virtual ward team share information with me?

The virtual ward team will ask if you have the patient's consent. If the person cannot make decisions, then as long as you are acting in their best interests, information may be shared. Equally, there may be information that has to be shared if you are providing care to prevent putting the patient's health and wellbeing at risk if you don't have the full information.

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I've received all the necessary information needed to care effectively by the virtual ward team

# What if I don't agree with the virtual ward team's health judgements based on what I know of my relative as an unpaid carer?

If you have concerns about the decisions being made, it is important to raise these as soon as possible directly with the healthcare team involved. It may help considerably if you can provide a strong case for why you disagree – with any evidence you have of their health condition or medical history, for example. If the issue persists, you could ask for a copy of their complaints procedure. You can find more advice about this here: carersuk.org/help-andadvice/practical-support/arranging-care-and-support-for-someone/making-complaints/

I've raised any concerns I may have about the health decisions being made by the virtual ward team for the person I care for

#### How will we understand what technology is being used?

Do you have enough information about how the technology you are being asked to use works, what's being used and why, and how any data is recorded? For example, are there any readings they want you to look for, like blood pressure? One of the nine principles of a virtual ward is to provide patients (and/or their carers) with adequate information to allow informed consent and understanding of the care provided or to support the use of equipment or digital technology such as mobile phones, apps, web-based tools or devices you can wear.

Make a list of any worries. It may be helpful to make notes of a conversation, ask for a repeat demonstration or ask for links to further information. Be sure to ask what happens if there is an issue and how services will know and respond to this.

The virtual ward team has a responsibility to ensure that the person needing care understands the technology that will be used. As their unpaid carer, you can ask to be involved and informed if that person is able to consent, or if you have Power of Attorney for health and care decisions, or acting in their best interests under the Mental Capacity Act if they are unable to make their own decisions.

Technology can be brilliant in highlighting problems early, but it's good to be confident about how it works and to understand it.

I've asked about the technology that will be used and written down the responses so that I know what will happen

## Are there extra costs involved in running the equipment in my house?

Some of the technology needs very little energy to function, but it depends on the technology or equipment being used. If you are concerned, you should ask about this. In most cases monitoring equipment is provided. It can include a tablet for communication and does not rely upon wifi or a good internet connection. Spot monitoring equipment will usually have enough charge for the duration of the virtual ward. The NHS could provide a personal budget to cover the costs.

### How best can I remember all the information?

You could make notes every time you have a conversation with the healthcare professionals you are in contact with and keep all information that is shared with you. This could include notes of who you meet with any key dates and information about treatment or medication side-effects, for example.

Write down any questions that you might have to come back to. You could also ask if you can record key conversations with any health professionals so that you can return to them. This might be particularly helpful if you find verbal or written communication with professionals challenging.

It's also a good idea to try to keep all important information in one place. That way you can keep track of it and refer to it when you need to.

- **I've made a note of key conversations and saved information that's shared with me**
- I've made a note of questions I want to ask when I speak to or connect with key people
- I've looked at the Jointly app (jointlyapp.com), which can help to log information about the person I care for and coordinate with others (eg, my sibling(s) / son(s) / daughter(s) / partner)

#### How do I find out what happens next?

Make sure that you ask the virtual ward team what the next steps are and make a note of the response. If the condition of the person you care for changes (ie, gets better or worse) then the outcomes might change. It doesn't matter how many times you ask this question if you are worried. Make sure you make it known to anyone in the team if you are unsure about anything in the virtual ward.

#### I've made a note of next steps and asked for answers to questions I wasn't sure about

### What happens if the person I care for gets worse?

Make sure that you have all the right contact numbers and that you know when to call someone in the virtual ward team, when to call 999 or 111.

The person you care for and you, as a carer, should have been provided with relevant information. This is one of the nine principles of virtual wards. You should know who to contact if their symptoms worsen, including out of hours. The team has a responsibility to make sure that there are clear pathways to help recognise any early signs of deterioration and the right processes in place to maintain patient safety if this is the case. All staff should have received training on these processes so that everyone knows what is supposed to happen.

I know who to contact if the condition of the person I care for gets worse

#### What happens when the virtual ward admission ends?

Make sure you get a clear, personalised care plan from the virtual ward team that details what happens next. This may include getting a more in-depth assessment to develop a coordinated and integrated plan for treatment and long-term follow up or being linked with other community services. As a carer, you have a right to be consulted and involved in what happens next.

You are also entitled to a carer's assessment if you haven't already had one. You can read more about what a carer's assessment is here: carersuk.org/help-and-advice/practical-support/carers-assessment/

It's not a test, but a discussion about your needs as an unpaid carer and the outcomes that you want to achieve. It may be useful to make a note of what has been said.

**I'm aware of what happens once the virtual ward admission ends** 

# I think I'll be providing unpaid care for longer – what should I be doing to support my health and wellbeing?

Planning to take a break and having cover is important. If you can, try to reach out to family members or close friends if you need some additional support. Even if they are unable to look after the person you care for, they could perhaps ease some of the pressure on your shoulders by, for example, offering to do your shopping or running other chores now and again to give you a break. There are some suggestions here:

carersuk.org/help-and-advice/your-health-and-wellbeing/taking-a-break/

If the person you care for is going on to have Continuing Healthcare provided by the NHS, then the team is responsible for making sure that you have sufficient breaks.

There are also other ways of supporting your health and wellbeing: carersuk.org/help-and-advice/your-health-and-wellbeing/

Remember, you can ask for a rapid carer's assessment to discuss the outcomes that matter to you and the support you need. Being able to have a carer's assessment is a statutory right.

If you need to combine work with your caring responsibilities, it may be possible for you to request a flexible working arrangement to help. Many employers make informal arrangements for flexible working. Check your internal work policies and remember, you have the legal right to request flexible working if you have been an employee with 26 weeks (six months) of continuous employment at the time you make an application. Check out your rights here: carersuk.org/help-and-advice/work-and-career/your-rights-in-work/requesting-flexible-working/

## Key checkpoints:

The purpose of the checklist below is to help you and the person you care for become familiarised with a virtual ward. It may be helpful to ask yourself the following questions:

- 1. Do you understand what virtual wards are?
- 2. Does the virtual ward team know that you are the unpaid carer (and that there may be other family members who also need to be identified as unpaid carers)? Are you being involved in all the assessments and discussions?
- 3. Have you asked to be recorded on the patient's record that you are their carer? This is important because as an unpaid carer, you should be involved in the patient's diagnosis, care and treatment.
- 4. Does your GP know you are a carer? Get in touch with your GP and ask to be recorded as a carer on your own GP patient record. This is really important so that in the future you can be called for free vaccinations (eg, flu or COVID-19) and health check-ups.
- 5. Are your needs being taken into account? Has the virtual ward team checked that you are willing and able to care?
- 6. If the person you care for is being discharged from hospital, are you aware of your rights as an unpaid carer?
- 7. Have you asked for a carer's assessment? As an unpaid carer, you have a right to an assessment to ensure that you are both willing and able to care. If you work and are unable to take time or juggle work with care, you can say 'no' to caring and they would have to make alternative arrangements.
- 8. Do you have the right information, advice and skills to be able to care? You can ask to have the right information. The NHS has a responsibility to ensure that the patient is cared for safely and well and to protect your own health and wellbeing.
- 9. Do you need help coordinating care with family and friends? Think about using our Jointly app (jointlyapp.com/) to coordinate care. There can be a lot to remember.
- 10. Do you have a contingency/emergency plan in case you're not able to care at short notice? We have an online tool here that can help: carersdigital.org/mybackup/
- 11. Do you know who is in charge of your virtual ward? Make a note of their name and who to ring if you have questions or are unsure.
- 12. Have you asked all the questions you have about the virtual ward? It's a good idea to write down and record all your questions and the answers.
- 13. Have you raised any concerns you may have about the health decisions being made by the virtual ward team for the person you care for?
- 14. Are you comfortable with the technology that is being used?
- 15. Do you know who the main named person is who you can contact if you have any issues (eg, if there is an emergency or if the tech fails)?
- 16. Do you know what happens once the virtual ward comes to an end?
- 17. If you aren't able to start or continue caring, other arrangements may need to be made to help the person leaving hospital stay safe and well.