

Carers and Hospital Discharge

Toolkit for London Hospitals and
Community Providers



3	Introduction
4	Context
6	Carers Care Pathway
8	Step One: Identification
14	Step Two: Welcome and recognition
18	Step Three: Assessment and support
24	Step Four: Involvement
28	Step Five: Transition
32	Hospital Carers Checklist Tool
36	General Information
40	Acknowledgements



Introduction

As the NHS is now in its 75th year I remind myself that I am a veteran carer of 58 years and so have seen many changes and developments. It is now so important to remind everyone of the progress that has been made and that good things are happening, despite the challenges. As the NHS England London region 'Carers and Hospital Discharge' learning event on July 12th 2022 and the subsequent follow up event on the October 5th 2022 so amply demonstrated, recognising carers as genuine partners in strategic design and co-produced delivery of healthcare can enrich and transform good outcomes for often very complex conditions.

The London region events clearly demonstrates the possibilities and the value of carers' 'lived experience' in supporting good recoveries for their relatives and ensuring confident and more rapid discharges to home and community. In recognising carers' rights, roles and responsibilities, the Health and Care Act has formalised the spirit of co-production and personalised care with and not only for carers and those they support - and this resource pack illustrates how we can make best use of these new opportunities.

The digital challenges on the day were skilfully resolved and for me they are a reminder that working together, we can resolve any of the difficulties which inevitably arise at times of change! I reflected that in 1948, at the birth of the NHS, we had no technology but huge good will and ambition to transform the health of the UK and its citizens. 'Carers' were unrecognised and hospitals were regarded as the pinnacle of healthcare. Now we have technology, community, hospitals and most importantly we have carers themselves recognised, valued and key players across the whole landscape of the NHS - July 12th and October 5th for me was part of the celebrations around the new NHS and the shared journey we are all on.

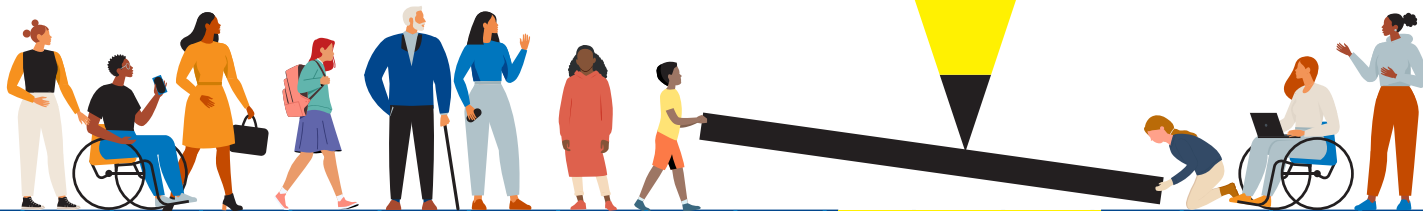
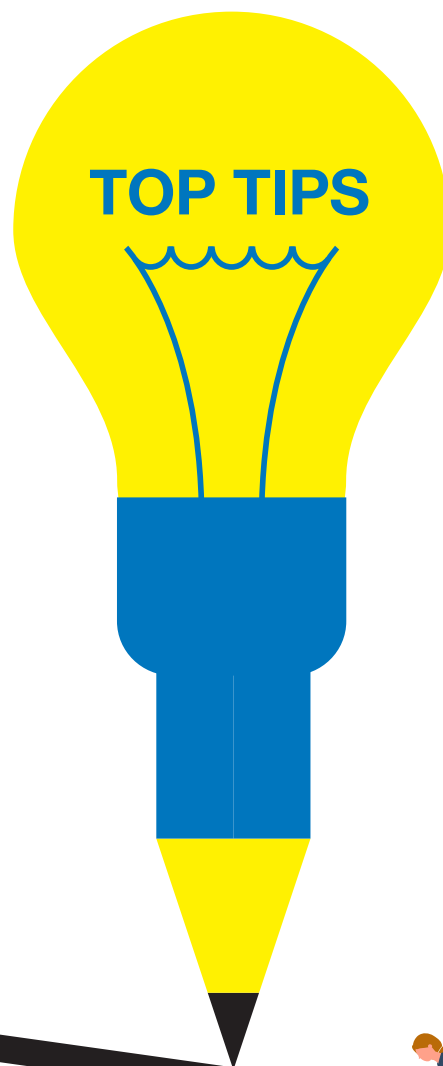


Dame Philippa Russell DBE

Context

This resource has been created as a toolkit for London hospitals and community providers and provides action-orientated 'Top tips' for good practice, aimed at improving outcomes for all carers through their hospital journey.

The toolkit attempts to bridge the operational and realisation gap between the *new hospital discharge and community support guidance* (March 2022 updated July 2022) and the, Supporting information for *Integrated care systems (ICS) leads Enablers for success: virtual wards including hospital at home* (April 2022) guidance



and is intended to help providers improve the experience of carers during hospital discharge or during an admission/discharge to a virtual ward.

The design is based on the Surrey Carers Pathway (**Surrey Carers Strategy 2021-24 Appendix 8**).

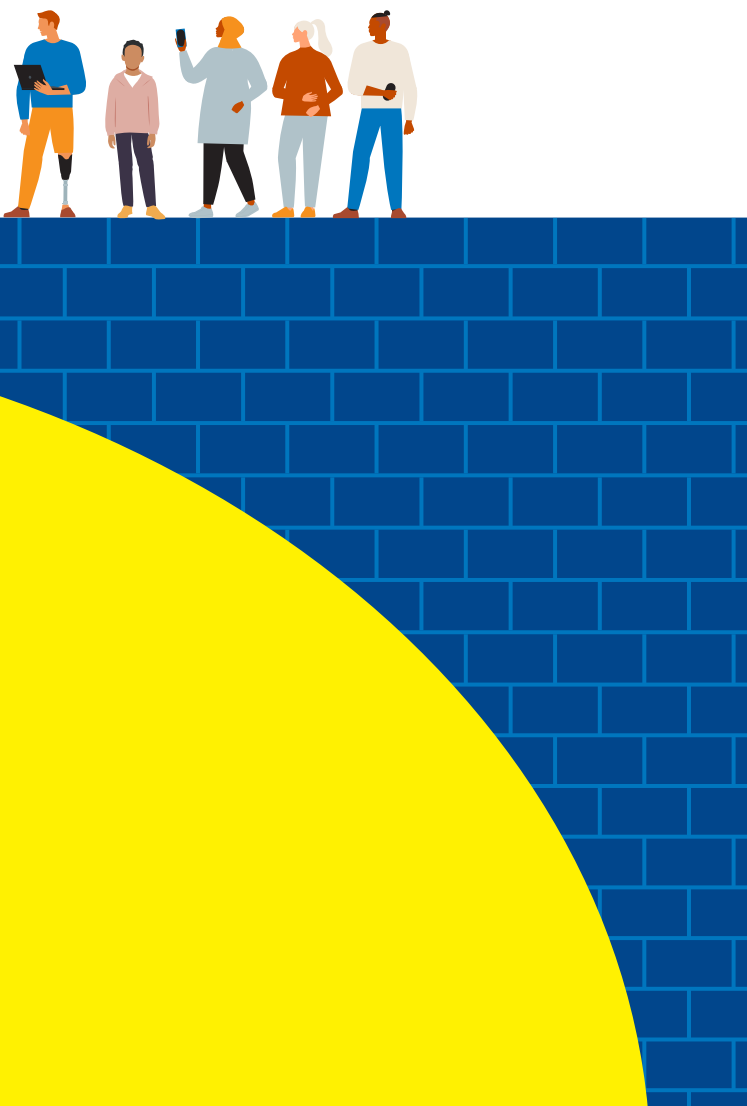
The resource highlights practical measures which have been tried and tested in London and elsewhere and provide a basis for operationalising the statutory guidance.

Many of the practical tools described in this document sit within a wider context of a 'carer friendly hospital' approach and should not be viewed in isolation.

It is the ambition of the NHS Commitment to Carers team to support acute and secondary care providers to embed carer friendly practice. This transformational work to improve the experience of carers of all ages, including young carers, in hospital discharge and virtual wards will help provide an evidence base for future quality assurance subject to minimum carer datasets being established and linked across systems, including that which GP practices hold.

The recent Nuffield Trust Report *Falling short - How far have we come in improving support for unpaid carers in England?* states:

“Despite legislative change to provide parity of esteem for carers, evidence suggests that carers’ needs are still not always considered in policy decision-making or in assessments of policy impact – indeed they can be overlooked entirely or considered only as an afterthought. One recent example of this is the policy of ‘discharge to assess’, where the negative impacts on unpaid carers of rapid hospital discharges, measurable in terms of costs to carers’ physical and mental health, have been largely brushed under the table – with 53% of carers reporting that their caring responsibilities were not considered, they were not kept informed and they lacked information about how to support their relative after discharge”

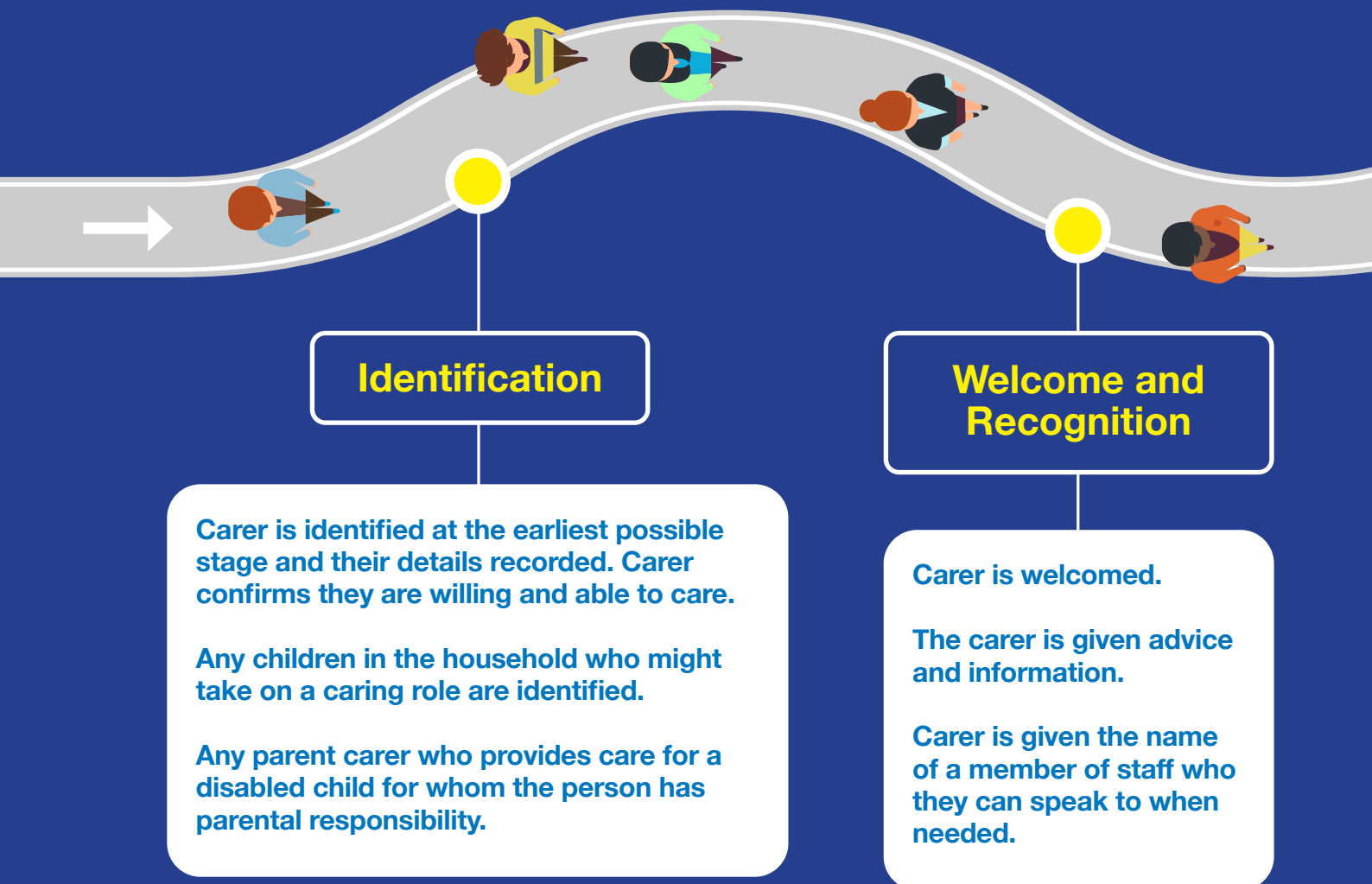


Carers Care Pathway

The Surrey Carers Pathway is a way of helping to ensure carers receive the type of support they need at the right time. The Surrey Carers Pathway was designed to serve two purposes: to fit within existing pathways familiar to community health care and hospital staff; and to help health care staff identify, recognise and support carers. There are other carer pathway models used elsewhere in the country and these are all very similar.

The five-step pathway was originally co-designed by carers and professionals in Surrey in 2015 and was updated in 2021.

The pathway has been reviewed by the NHS England London region health and social care partners, in the light of the recent guidance and additional steps identified. Providers will need to consider who is responsible for delivering each part of the pathway.



Carer is informed they have the right to a statutory carer's assessment of their own needs. The benefits of this are explained. Support needs of the family and children are identified.

Carer is referred to the local carers support service or given information on how to self-refer.

Staff ensure carers are given the practical skills and training to allow them to care.

Assessment and Support

Carers have seamless experience when moving through service(s).

Transition

Involvement

Advice is given to carer about the partnership approach to delivering care where the patient, carers and health and social care professionals are all seen as equal partners.

Step One

Identification



Identifying carers is the first step to providing them with the support they need to maintain their own mental and physical health and wellbeing. A key barrier to providing information and support for carers is that they are frequently not identified. People may not see themselves as carers, rather seeing caring as an extension of their familial role: daughters, sons or partners or as a good neighbour or friend. As such, the term carer does not always resonate with them. Supporting friends and family to recognise their caring role and that the term 'carer' is valued and recognised in law and provides access to a range of advice, information and support. In addition, becoming a carer can be a gradual process, and carers may not recognise the changing nature of their relationship with the person they care for. Similarly, many carers are not identified by health and social care practitioners. These are commonly termed 'under-represented carers': they do not access the support available, often because they do not know it is there. In relation to young carers, the other barrier is that they may often not be seen by health and social care professionals because they are at school/college.

That is why having systems and processes to help identify potential young carers in place and adopting the principle of professional curiosity is so important.

Additionally, health and care staff may use the term carer interchangeably with that of a paid care worker or as the person who is recorded as 'Next of Kin' which may cause further confusion.

With 7 out of 10 carers starting their caring journey in an NHS setting there is a clear opportunity for health staff to support early carer identification.

It's the responsibility of the admissions staff to provide the person and their family, carer or advocate with an opportunity to discuss their care. They should also provide the following information:

- reason for admission
- how long they might need to be in hospital
- care options and treatment they can expect
- when they can expect to see the doctors
- on any special arrangements to support carers, for example the hospital's **Patient Advice and Liaison Service (PALS)**. If the hospital has a carer champion or dedicated carers' space. If a carer passport scheme is in operation and what this offers such as options for hospital car parking charges concessions, access to staff canteen or overnight accommodation.
- the name of the person who will be their main contact including all their contact details (this is not necessarily the discharge coordinator)
- on all the possible options for transport home when they are discharged from hospital including eligibility for NHS patient transport, or if there is a volunteer driver scheme. This will be important for discharge from London specialist hospitals where the distance home may be considerable.
- care and treatment after discharge.





In the words of one nurse:
“It’s easy to identify the carer, they are the ones who are usually asking all the questions, it’s not rocket science!”

How and when to identify a carer/s?

Sample questions for admission forms

1. Who looks after you when you are at home?
2. Are there any children or other members of your household who help to look after you or who may be affected when you are in hospital?
3. Are you happy for us to talk and involve this person in discussion about your health and care whilst in hospital?

- Actively seek to identify carers at first contact (in line with the Care Act 2014 and Children and Families Act 2014) at every entry point into hospital, including accident and emergency departments. Ensure policies and systems encourage the identification of carers (including young carers).
- Be aware that some people might not view themselves as a carer or may not ask for support as they consider it outside that member of staff's professional role.
- Where the patient lacks mental capacity staff may need to approach visitors, social services or the patient's GP to gain information on the care arrangements in the patient's home.
- Develop hospital resources such as posters and leaflets to encourage people to self-identify as carers. It's worth looking at the **posters and resources** developed by Carers Trust around the **Triangle of Care model** used in mental health trusts. For more information please email: **Triangle of Care**
- Ask the patient with care and support needs who helps and supports them (apart from paid practitioners) when at home— this may not be a family member or someone who lives with the person, and may be multiple people including children in the household.

If a carer/s is identified:

- Record their details on the patient records (if the patient gives their consent, if the patient doesn't give consent, record the carer's details separately as they still have rights).
- If there are multiple carers ask them to agree who will be the point of contact for them all.
- If consent is not provided by the patient, carers still have their own rights to advice and support, therefore record carer status on their own records (if the carer gives their consent).

How to guide: **NICE Adult Carers Support Quality Statement One**





TOP TIPS

Language is key - If you say “Do you have a carer?” or “Are you a carer?” your results will be very different to if you ask “Is there anyone who helps to support you when you need help at home?”

Do not confuse ‘Next of Kin’ with carer. They may be completely different.

Remember the patient themselves might be a carer as such it will be important to ascertain whether the person they care for is receiving care during their absence.

Work with your local carers service who might be able to provide you with some posters and leaflets to help support carers to identify themselves.

Provide staff carer awareness training. This is crucially important. Often your local carers service are willing to offer this. To find your local carers service click on this link: **Carers Support Service search**. Some carers support services now provide staff carer awareness training. These courses benefit from being co-produced by carers and often delivered by carers themselves. It is worth asking your local carers support service whether they provide this service.

Consider offering CPD accredited carer awareness training more broadly across the hospital/community service such as offering training to non-clinical staff and to volunteers working in the hospital.

There are many Carer Awareness E-learning courses available, including
Queen’s Nursing Institute
Carers UK E-learning



Some carers support services are commissioned to provide carers support within a hospital setting. A good example is the HSJ award winning **Hospital services - Devon Carers.**

Use this as an opportunity to identify staff combining work with care. A good example of a **working carers passport** has been developed by the West Yorkshire Integrated Care System.

Do not get hung up on the 'C' word. If people are reluctant to take on the term carer that is their choice. They are still entitled to advice, information and support. Ask instead 'Do you look after someone?' A good resource is the **NHS website Support and benefits for carers** also the Carers UK – '**Looking after someone**' guide and

remember it is not sufficient to replace the term carer with family as not all carers are relations.

Some patients may feel uncomfortable telling staff that someone does support them with their care needs, as it may make them feel vulnerable. This could raise concern about the strain this is causing for the carer or a denial of the patient's need for support. Each of these reasons would require a different response from staff. NHS Cumbria, Northumberland, Tyne & Wear Foundation Trust and have produced a **Common-sense confidentiality – A guide for carers, families and friends.**

Young carers will need to be supported differently from adult carers and would benefit from a different kind of support. Staff need to be aware of this and refer appropriately. Consider developing your own young carer hospital information. Examples such as **Epsom and St Helier University Hospitals NHS Trust Young Carers Information Leaflet.**

Take advantage of national carer events to promote carer awareness, **Young Carers Action Day** (March), **Carers Week** (second week in June) and **Carers Rights Day** (last Thursday in November).

Make sure your hospital website includes advice and information for family and carers. Check that it is easily accessible, preferably within two clicks. An example of best practice is Surrey and Sussex Healthcare Trust **carers advice pages.**

You may also consider putting posters and leaflets in the main reception, A&E and discharge areas (including information in relevant languages) to alert carers to useful sources of information and advice.

Consider establishing a network of trained and committed carer champions who in turn can support their colleagues with carer friendly practice. There are a number of role descriptions for example, those developed by **Carers Federation good practice guide.** A good example of a carer champion project is **Greater Manchester Mental Health NHS Foundation Trust Carer Champion.**

Find out who the hospital carers lead is and ask to read the hospital carers policy.



Step Two

Welcome and recognition



Carers can struggle for recognition and support from health professionals. Involving carers in decision-making and recognising their role as expert partners in care serves to benefit patients, carers and the NHS alike.

It is a legal duty for local authorities to provide information to families and carers to support them in their caring role. Information provision must meet the requirements of the **Care Act 2014 (Part 1)** and **Children and Families Act 2014**. It is the duty of the NHS to cooperate with the local authority to ensure carers are identified and provided with information regardless of setting.

Carers are often the only part of the care team and the care plan that remains consistent so if we do not understand and meet carers' needs we are not going to achieve the outcomes we all want.

Following a systematic review study conducted by **American Association of Retired Persons (AARP)** where they compared discharge planning in usual care transitions with those where the carers had been integrated, these were associated with a 25% reduction in hospital re-admission.

It is important that hospital staff have a good understanding of the rights and the benefits for carers so that they are able to explain them. People are unable to exercise their rights if they remain unaware of them.

Information for carers should be:

- co-designed with carers
- up to date, regularly reviewed and meet the **NHS Accessible Information Standard**
- plainly worded, clearly presented and free of jargon
- proportionate, set down in manageable chunks of information which use visual aids or pictures
- culturally sensitive
- explaining carers rights and how to access social and community support for carers
- providing useful further sources of information and support such as the local carers support service.



How do we recognise carers?

Carers have a wealth of knowledge about the person they care about and are often key to understanding the person's needs and preferences. We know from research that many carers feel both invisible and ignored. This can particularly be the case in relation to young carers where professionals sometimes see them as 'just' a child, even though they may be the primary carer at home. A young carer from Norfolk worked with his local hospital to produce this film about his experience with professionals - <https://youtu.be/CJXvROXEa3I>

The attitude of professionals towards them and the person they care for is very important in both ensuring that the cared for person receives the help they need but also to the carers' levels of frustration and stress, and sense of their own worth. When the carer's value is recognised and respected as a core member of the team around the person, they care for everyone wins. Providing the person gives consent and their wishes remain central, carers should be supported to actively participate in decision making and care planning for the person they care about. This will help to ensure that care planning is based on accurate and detailed information, as well as supporting the carer in their role and helping to sustain the caring relationship. When people lack capacity to give consent, the involvement of carers should be in line with the **Mental Capacity Act Code of Practice** and the **NICE guideline on decision-making and mental capacity**.

Carers want their role to be recognised by staff. They need contact with staff for reassurance that they are doing the right thing, a named person they can talk to, who would get to know them and the person they look after. They also need continuity in the support they received.

How to guide: **NICE Adult Carers Support Quality Statement Two – Working with Carers**



TOP TIPS

At admission carers can feel overwhelmed so make an early appointment for carers to speak with a member of staff to ensure the initial assessment is balanced, correct, and considers all factors. This is especially true when the patient is a child or lacks mental capacity.

Confidentiality is an often-cited issue to not working with a carer but even where the patient has not provided consent there is nothing to stop you listening to the concerns raised by carers or providing them with general information not linked to the patient (e.g., around the condition/medication).

Consider establishing a 'carer/s champion role' and example of this operates in Greater Manchester System **Meet our Carer Champions | Greater Manchester Mental Health NHS FT (gmmh.nhs.uk)**. Surrey and Sussex Healthcare Trust operate a volunteer Carer Champion role. This can take pressure off clinical staff.

Compassionate conversations

Get to know the carer and be proactive about asking the carer how they are coping but be mindful that carers may often not feel able to say how they are doing in front of the person that they care for. Ask if they have any questions. Ask the carer what usual behaviour is for the patient. When establishing a relationship with the carers recognise where there is carer trauma and if this is an unsupported need. If so, ensure this information is shared with social care practitioners who will undertake a full carer's assessment.

Find out if your hospital allows carers to provide personal care during hospitalisation, if so, use this opportunity to transfer caring skills for example, safe moving and handling.

Think about how you ask the patient questions? For example, if asking 'Can you cook for yourself?' consider instead asking 'Did you cook a meal for yourself last night?' How questions are asked can make a big difference to the answers given.

Encourage carers to ask questions and check their understanding of the answers you have provided. Ensure they know who they can contact if they have any concerns or questions. This is particularly important for young carers who may not be confident in asking who they need to speak to. If it's a particular role, make sure the carer knows how to identify who that person is (e.g. do they wear a different uniform?).

The mental health '**Triangle of Care Self-Assessment Tool**' quality improvement tool can help provide a stocktake around how carers are welcomed and recognised within hospital.

Are carers provided with a Carers Information Pack or equivalent? Example of best practice is **Bradford District Care Foundation Trust**.

Does the hospital operate a carers passport scheme? Examples of best practice can be viewed here **Carer Passport schemes | Carers Passports**.

Has your hospital signed up to **John's Campaign**?

Check that the carer has been provided with a named contact and contact number.

When there is more than one carer, identify a main carer to communicate with, who can then cascade information to the rest of the carers/family. Ensure you record this on the patient records.

Carers UK's Digital Resource for Carers platform hosts a wide range of online resources including e-learning modules and the care-co-ordination app, Jointly, to promote wellbeing and resilience in caring. The Digital Resource for Carers includes e-learning, guides and comprehensive signposting, access to MyBackUp, a simple contingency planning tool for what might happen in an emergency.

Jointly App (accessible from the platform or at **www.jointlyapp.com**) can help carers create their own contingency plan.

Carers UK have provided a range of promotional materials including posters to have in waiting room areas and business cards to be made available at the reception desk as well as a unique free access code **www.carersuk.org/nhs-digital-resources**

Step Three

Assessment and support



Although the legal duties to assess carers support needs rest with local authorities there are many ways in which health staff can support the process. A key role is making sure carers know they have a right to an assessment and know how to request one. Staff can also ensure that parents know about rights for young carers.

Carers are often unfamiliar with how to care and may need support in managing the practical side of their caring role. Staff should pro-actively seek to use the period of hospitalisation to help demystify health jargon and seek to transfer skills and capabilities to carers who demonstrate an interest to learn.

For example - carers value a better understanding of:

- the condition, disability and needs of the patient
- managing medicines and any other clinical treatment/techniques agreed to be taken on by the carer
- preparing food and eating well and other dietary requirements especially in the case of stroke survivors
- personal care
- continence management including catheter care
- managing behaviour that challenges
- digital and assistive technology
- safe moving and handling, including using equipment and adaptations
- specific information about staying safe in the caring role
- financial advice including benefits and allowances and information and options for self-funders and where the patient meets eligibility criteria information on NHS funded and continued health care funding.

For many carers a period of hospitalisation may provide the first real break they have had from caring in many years. Staff should always demonstrate compassion around the caring circumstances and understand that if the carer wishes to use this time to have a well-earned break. Sometimes carers may need to be prompted to do this and be told, as kindly as possible, that its good for them to take a break and that the hospital staff are here to take over.

Hospital staff need to be able to explain to carers what support is available to them including what a **carer's assessment** is and what is the benefit of having one. This is also a good time to share with the carer information about their **local carers support services**. It is good practice for local authorities to have information for carers on discharge.

What is a statutory carer's assessment?

A carer's assessment is for carers over 18 years old who are looking after another adult over 18 years old who is disabled, ill or elderly. It is an opportunity to record the impact caring has on the carer's life and what support or services they may need. The assessment will look at, for example, physical, mental and emotional needs, and whether they are able or willing to carry on caring.

What is a statutory young carer's assessment?

A young carer's assessment should be part of the whole family approach.

The local authority has a duty to assess 'on the appearance of need' (e.g. without a 'request' having to be made, although they must also be provided if the young carer or the parent requests one) and the assessment must involve the child with caring responsibilities, their parents and any other person the young carer requests in the assessment process.

The assessment must look at:

- whether or not the young carer wishes to continue caring, and
- whether it is appropriate for them to continue caring
- any education, training, work or recreational activities the young carer is/or wishes to participate in.

Where a young carer's eligible needs are identified as requiring support, the local authority will have to:

- provide support directly to the young carer or
- demonstrate that the assessment of the person being cared for has provided adequate care and support to prevent inappropriate care being required from the young carer. (known as the whole family approach).

Local authorities are also encouraged to consider combining the assessments of people within the same family, for example those of the carer and the person being cared for, so that the assessments are linked and complementary. However, carers and the person they care for should always have the right to speak separately as well as jointly in any assessment. Similarly, assessments can sometimes be carried out jointly with another agency, such as the NHS, to ensure that all the professionals involved in a person's care are talking to each other when decisions about care are being made. This is true for parent carers and potentially **transitions assessments** (for young people and parent carers).

Carers UK Fact Sheet Carer's Assessments
Carers First Fact Sheet Carers Assessment

Value of having a statutory carer's assessment

A statutory carer's assessment provides carers with psychosocial and emotional benefits and may be viewed as a therapeutic intervention in its own right. A good carer's assessment will be a conversation between the carer and the staff members and be on what matters most to the carer and what will help them so that they can be better supported in their caring role. It should provide the opportunity to discuss all relevant aspects of their health, wellbeing and social care needs as well as work, education or training. It should follow a whole family approach. It is important that the carer knows that the assessment is not assessing 'how well' they are caring for the person they care for.



What should happen whilst in hospital?

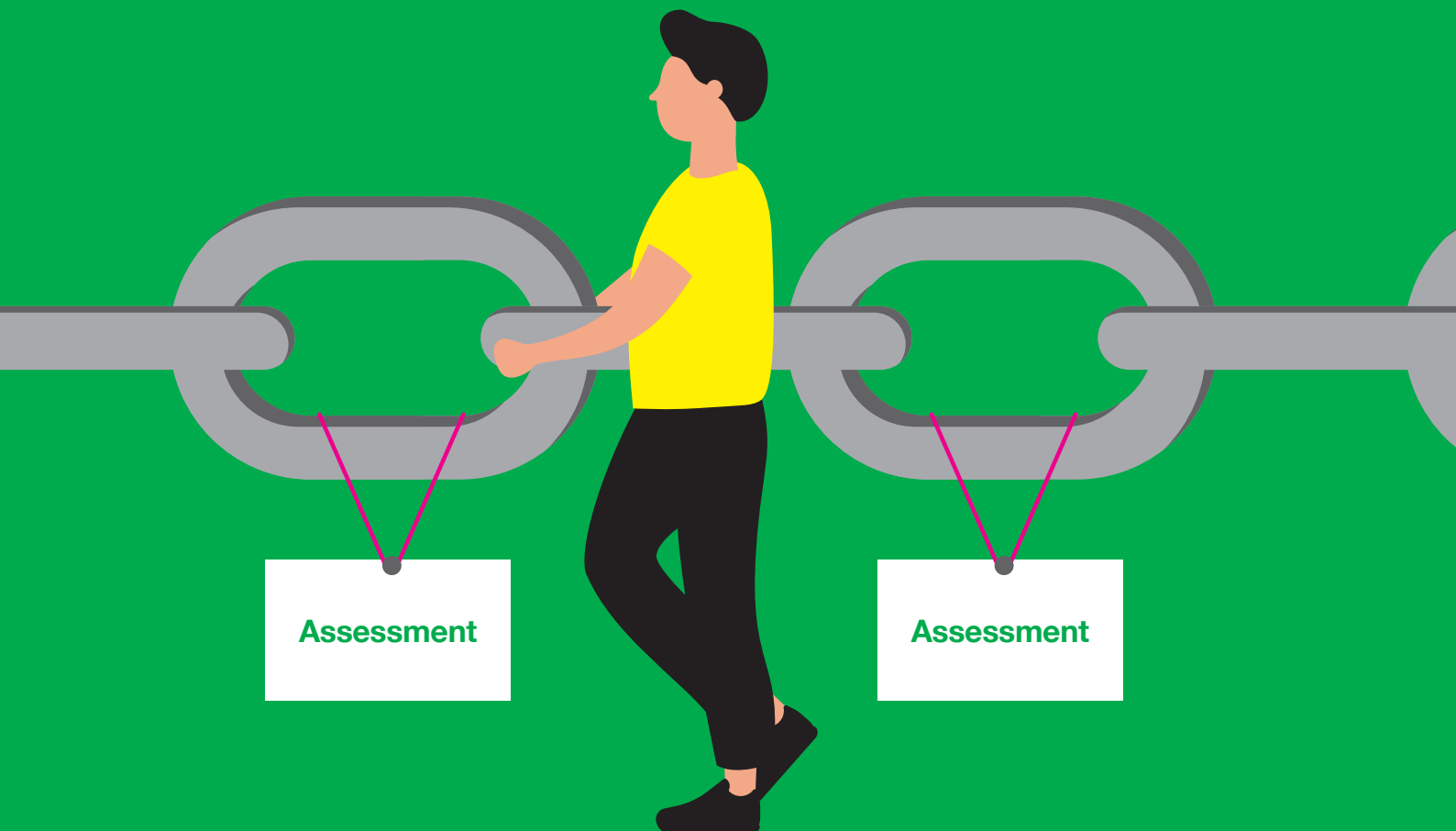
Whether carers are new to caring or have been caring for some time the carer's status should be reviewed during the patient's stay in hospital. An episode in hospital may lead to a patient requiring care and support for the first time. If there is an existing carer relationship, the level of dependency of the person they care for may have been exacerbated by this illness or treatment. Whether the carer is willing to assume, maintain or take on additional caring responsibilities should be clearly documented. These conversations are best taking place in private and separate to the patient.

If the carer is new to caring or the caring circumstances have changed and there is an appearance of need, they should be referred for a statutory carer's assessment. Sometimes these assessments are best left until after discharge, if this is the case it is important to identify any risks for the adult carer or young carer in the short term before discharge.

Some NHS providers are making use of carer risk assessment tools or holistic assessment tools to support safer discharges.

How to guide: **NICE Adult Carers Support Quality Statement Three – Assessing carers needs.**

Young carers and carers of children under the age of 18.





Support for young carers needs will be different to that of an adult carer and needs to be age appropriate. We all have a duty to protect them against inappropriate tasks and excessive levels of caring.



There are lots of non-statutory adult carer risk assessment and holistic needs assessment tools which have been developed including many condition/disease specific versions of these tools for stroke, cancer or dementia carers.

An example of a generic adult carer risk assessment tool is the **Carer Strain Index**.

Although primarily used in end-of-life circumstances the **Carers Support Needs Assessment** Intervention is a best practice example of a carers holistic needs assessment.

Support for young carers needs will be different to that of an adult carer and needs to be age appropriate. We all have a duty to protect them against inappropriate tasks and excessive levels of caring. Most areas now operate a young carers support service. Ask the parent for consent to refer the young carer to this support service. If the parent is reluctant to provide consent, seek to understand why and provide reassurance. Most young carers services are operated by voluntary sector/charities. Depending on their age, you may be able to refer the young carer without the parent's consent, but you should check with your local young carers service before doing so. Remember if you have concerns that the child is undertaking an excessive amount of caring you should refer them for a young carer's assessment. Please follow local children safeguarding protocols where appropriate.

Some hospitals have created a special area for carers often referred to as a carers lounge or hub an example of which is **Bedfordshire Hospital**.

Service providers should develop processes to support carers and other people important to the person to be involved in advance care planning, if the person approaching the end of their life agrees.

Conversation around advance care planning need to be respectful, compassionate, culturally appropriate and allow time for carers and families to process information.

Where children are concerned and in end of life circumstances it is not unusual now for the hospital/hospice to make provision for family and carers. Some like the **Royal Surrey NHS Foundation Trust** provide carer overnight complimentary bags and put up beds. It's good to check with the carer if they know the area and have some suggestions ready around where they might find accommodation near the hospital.

There are many practical guides to caring available. Some are condition specific.

Below are some good examples:

Public Health England – **Practical Guide to Healthy Caring**

Alzheimer's Society – **Caring for a person with dementia – Practical Guide**

Macmillan Cancer Support - **A guide for young people who look after someone with cancer**

End of life care - **Caring to the end – young carers information**

Remember to inform the carer about the hospital PALS and what its function is if they raise any concerns.

Step Four

Involvement



Where consent has been provided, staff and carers working together in equal partnership with the patient means their collective knowledge and expertise can be used to devise individual care and support plans to help support recovery for the whole family.

A member of the hospital-based multi-disciplinary team should be made responsible for providing carers with information and support. This could include:

- printed and digital information
- face-to-face meetings
- phone calls
- hands-on training, including practical support and advice.

What should happen before hospital discharge from the carer's perspective

- The carer and the person they care for can both be closely involved, as long as the patient provides consent. Where the patient refuses consent to provide information with the carer this choice must be revisited with the patient to explain the benefits to their on-going care and support. Regardless of consent the carer can still be supported in their own right and has the right to receive general information as well as being offered referrals to carer's support and for a carers assessment.
- A **discharge assessment** should be carried out to see if they need support once discharged.
- A **carer's assessment** should be carried out (or at least arranged), to see whether the carer will need support once the patient is discharged.
- Encourage the carer to consider registering an emergency plan in case anything happens to the carer which means they are unable to care. These will usually be offered by either the local authority or an external organisation on behalf of the local authority.
- A written care and support plan should be given to the patient (and a support plan for carers if they have had a carer's assessment or review of their carers assessment during the period of hospitalisation), which outlines the support required and how this will be provided. Mobilise offer a simple template form www.mobiliseonline.co.uk/emergency-planning-for-carers
- The support outlined in the care and support plan for the patient and the support plan for the carer should be put in place. This should include any carer contingency plan. It is important that any carer contingency plan is registered with the carers GP practice using **SNOMED CT Carer code1366321000000106**. Should an emergency arise this will allow first responders to activate the plan allowing for continuity of care for the cared for person.





Be pro-active about involving the carer in all discussions regarding care, medications, discharge and self-care advice.

Have a caring conversation. Conversation starters:

- How are things with you?
- We have all had a quite tough time lately, are you getting any support?
- How is your family coping?
- Are you getting any support from your employer?
- Did you have a good weekend?
- How are you managing to balance things?

Some hospitals allow carers to provide personal care during the period of hospitalisation. This allows carers to gain a better understanding of how the care and support needs may have changed for the person they care for. It means carers can make an informed decision as to whether they are willing and able to continue to provide care in the future.

Find out what your hospital policy and process is to support carers to actively participate in decision making and care planning for the person they care about.

Ensure carers are able to input into Multi-Disciplinary Team (MDT) meetings even if they are unable to attend in person. It should be agreed who in the MDT will lead on this.

Before the MDT:

- Check again that the carer has been identified and remains willing and able to care, especially in context of carers who combine work with caring.
- Decide who will contact the carer to discuss the person's admission and ensure the carer has the name and contact details of the lead.
- How frequently will the carer be contacted and who will do this?

- Has the carer received advice and information?
- Does the carer need an advocate? If so, has this been arranged?
- Does the carer need an interpreter? If so, has this been arranged?
- Where consent has been given, carers should be involved in all 'patient best interest' decisions. Where they are not, carers still have rights to general information and practitioners can always listen to carers concerns without breaching patient confidentiality.
- Has the carer been signposted to local carers support services?
- Has the carer been encouraged to consider contingency planning services, should their circumstances change?

At MDT

- Ensure the carer has a chance to share their point of view and raise any issues or concerns.
- Check with the carer that they understand what decisions have been collectively made.
- Ask what support needs they have and whether to refer them for a carers assessment, especially in relation to carers who combine working with caring.
- Where necessary ensure that families and carers are provided with information and support around future care provision for patients who are not returning home but to other care settings.
- Record all actions which have been agreed, who is doing them and by when.

NICE Guidance NG142 - End of life care for adults: service delivery lists inappropriate tasks for carers could include:

- personal care such as bathing and toileting;
- carrying out strenuous physical tasks such as lifting;
- administering medication;
- maintaining the family budget;
- offering, precociously mature, emotional support to the adult e.g. if, in effect, the child is "parenting their parent".

Where there are any concerns staff should always follow their internal safeguarding policy.

Remember think simple solutions, a carer's life is already busy!



Step Five Transition



A safe transition of care to the carer should be given the same status as any other transfer of care.

The discharge coordinator or the delegated member of the MDT should arrange follow-up care. They should identify practitioners (from primary care, community health, social care, housing and the voluntary sector) and paid care staff who will provide support when the patient is discharged and record their details in the discharge plan.

The discharge coordinator should discuss the need for any specialist equipment and support with primary care, community health, social care and housing practitioners as soon as discharge planning starts. This includes housing adaptations. Ensure that any essential specialist equipment and support is in place at the point of discharge. This should involve the carer and provision should be made for any training needs the carer might have in using the equipment.

Once assessment for discharge is complete, the discharge coordinator should agree the plan for ongoing treatment and support with the community-based multidisciplinary team.

Staff should discuss with the person how they can manage their condition after their discharge from hospital. Provide support and education, including coaching, if needed. Make this available for carers as well as for patients using services.

The discharge coordinator should provide people with complex needs or who need end-of-life care, their families and carers with details of who to contact about medicine and equipment problems that occur in the 24 hours after discharge.

The discharge plan should take account of the carer's:

- willingness and ability to provide support, recognising that the patient may be discharged with very different care needs to those prior to admission and that the level of care and support required may now have increased
- carers availability due to other commitments such as work
- sustainability of the caring circumstances post discharge (carers age, mobility, physical capacity etc)
- circumstances, needs and aspirations
- relationship with the person
- need for respite/a break from caring.

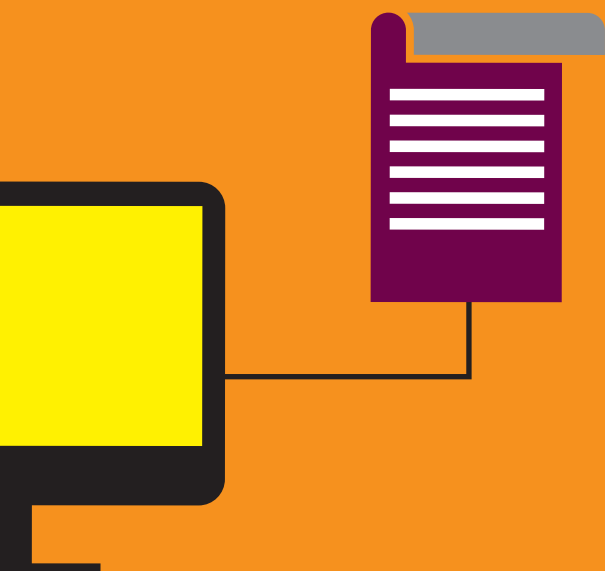
A member of the hospital-based MDT should discuss the practical and emotional aspects of providing care with potential carers.

Ensure that training is available to help carers provide practical support. The relevant multidisciplinary team should offer family members training in how to care for them. For example, this could include techniques to help someone carry out everyday tasks as independently as possible. Training might take place in the hospital, or it may be more useful at home after discharge.

If the patient is being discharged to a virtual ward, training in the use of any digital monitoring or use of equipment such as telecare should be provided to the carers. The British Geriatric Society notes the importance of support and training in the use of technology-enabled care, with special attention to patients and carers who may not feel comfortable using digital monitoring.

[Bringing hospital care home: Virtual wards and hospital at home for older people]

The community-based MDT should review the carer's training and support needs regularly (as a minimum at the person's six-month and annual reviews). Take into account the fact that their needs may change over time.



What should happen on the day of discharge from the carer's perspective

- Appropriate patient transport should be organised if it is required. Ideally transport should be arranged between the hours of 10am-4pm to avoid potential stress for carers caused by the person they care for returning home very late in the evening or in the early hours of the morning. If this is not possible staff should ensure that the carer is kept fully informed of the estimated time person will arrive home and given as much notice as possible – this is particularly important for carers who are balancing caring with paid employment or education/training
- Patient and carer should both be given copies of the care or support plan, if a carer's assessment has taken place during the period of hospitalisation the carer should be given a copy of their care and support plan
- A discharge letter should be sent to the GP of the patient within 24 hours
- Medication and any equipment needed at home should be provided, as well as instructions and information about its use
- Details of who to contact with any concerns such as medication side effects or equipment failure
- Any necessary support should be put in place to start on the day of discharge.
- Information about who to contact if any problems arise in the immediate period after discharge, in most cases this will probably be the GP or the 111 service.

Post discharge

Support should extend beyond discharge itself.

- Communicate with the individual and, where relevant, their unpaid carers to track and manage the individual's recovery
- Ensure that any change in the support needs of the individual (or their carer) takes place at an appropriate time.





Patient facing leaflet

Hospital Discharge Patient Leaflet

Carer facing resources

Carers UK produce a number of useful fact sheets for carers including:

Coming out of hospital

Mobilise **Carers Guide to Hospital Discharge**

Carers First Carers Support have produced a simple **Carers Hospital Discharge Guide**

Action for Carers Surrey have produced a **Hospital Discharge Guide** this includes a carer's checklist

West Yorkshire and Harrogate ICS developed a **Discharge Toolkit** during the pandemic containing a number of resources supporting carers at the point of discharge, providing them with information and support to potentially prevent a readmission to hospital.

This included:

1. Some basic information about personal protective equipment and information about further training available for carers if needed.
2. An introduction to some of the practical information a carer may find useful starting their caring journey.
3. A template supporting carers to make a contingency plan for a scenario where they will be unable to care.
4. Information about how to access further support locally.
5. Information about resources available online to support psychological well being.

They also developed a **Young Carers Toolkit**

Hereford and Worcester Health and Care NHS Trust have developed a number of resources including a **Carer Checklist**.

Enfield Carers Centre – **Involving Carers in safer in hospital discharge**

At this point in the hospital journey families and carers may need advice around NHS Funded and Continuing Health Care (CHC). Although a complex process for carers to understand the **Surrey Carers and CHC Guide** can be helpful.

Or Beacon – **Advice on navigating CHC post Covid**

Some hospitals now share a carers discharge letter. There are many templates available. Including **Helensburgh and Lomond**



Hospital Carers Checklist Tool

Stage 1

Have you identified the recognised carer who is looking after your patient?

☐ Yes

☐ No

If no have you made a referral to social care?

☐ Yes

☐ No

Are there any children in the household who are providing care or who may be affected?

☐ Yes

☐ No

What support have you provided to the carer? For example

☐ recorded carers details in hospital records

☐ involve carer in planning

☐ involve carer in care planning

☐ offer carer passport

☐ provide advice on patient medication and care

☐ provide carer information pack

☐ refer carer to local carers support services

Have you asked the patient if they are a carer?

☐ Yes

☐ No

If yes ask if arrangements have been made for the person/s they care about?

☐ Yes

☐ No

Anything else



Resources to help you support the Carers at each stage

NHSE Commitment to Carers

NICE Guidance 27 – Transition between inpatient hospital settings and community or care home settings for adults with social care needs.

NICE Guidance 150 – Adult Carers Support

Discharge to assess quick guide

Children's Society Health services and support (Young Carers)

Carer Contingency Planning

SNOMED CT code	Term Description	Definition for NHS LTP delivery and associated metric
1366321000000106	Has Carer Contingency Plan/ Has Carer Emergency Plan	Carer has contingency plan in place for a situation when they cannot provide care and relevant information is accessible to professional

Hospital Carers Checklist Tool

Stage 2

Have you checked the carer is willing and able to care?

- ☐ Yes
☐ No

Have you provided the carer (or a young carer and their family) with relevant information?

- ☐ Yes
☐ No

Step 3

Have you referred the carer to:

Social Care – Carer's Assessment

- ☐ Yes
☐ No

And / or

Local Carers Services

- ☐ Yes
☐ No

NB this includes any young carers identified.

Step 4

Has the carer been able to input in the discharge planning?

- ☐ Yes
☐ No

Has it been ascertained whether the carer is willing and able to provide care post discharge?

- ☐ Yes
☐ No

If the patient's care and support needs have changed during the period of hospitalisation has the carer been made aware of this? Are they still willing and able to care?

- ☐ Yes
☐ No

If the patient is being discharged to a different care setting has the carer been given information of what options are available to them and sufficient time to investigate these?

- ☐ Yes
☐ No



Step 5

Has there been a conversation with the carer regarding the anticipated date of discharge and any challenges identified?

- ☐ Yes
☐ No

Has the carer been offered advice and information on the patient's condition?

- ☐ Yes
☐ No

Has the carer been offered training on how to care for the patient?

- ☐ Yes
☐ No

Has the carer been given training on how to use any equipment provided safely including any health technology equipment?

- ☐ Yes
☐ No

Have the transport requirements of the patient been discussed with the carer?

- ☐ Yes
☐ No

Has the carer been informed what time to expect the arrival of the patient?

- ☐ Yes
☐ No

Has the carer been given advice and information on patient's medication?

- ☐ Yes
☐ No

Has the carer been provided with a copy of the discharge plan?

- ☐ Yes
☐ No

Has the carer been provided with a named contact and contact number to call if they have any concerns post discharge and does this cover out of hours services?

- ☐ Yes
☐ No

General information

Each ICS will have its own carers strategy some of these have been delegated to Place (borough). Example of a hospital carers strategy which aligns to the wider ICS Carers Strategy can be found **Carers Strategy 2021-24: Surrey and Sussex Healthcare NHS Trust**

This also includes an example of a Hospital Carers Action Plan.

To read the HSJ award winning Torbay and Devon Hospital Carers Support Service evaluation report **[click here](#)**

Partner Websites

Carers UK

Carers Trust

Carers First

Mobilise

For more information and examples of best practice in NHS carer friendly practice

The NHS England Commitment to Carers Programme have their own dedicated pages on the Future NHS Collaboration Platform

[Future NHS Collaboration platform](#)

Join our Commitment to Carers

London NHS England Regional Carers Lead Contact:
Email **england.nhsthinkcarer@nhs.net**

Co-production

The development of this toolkit has been informed by Government legislation, national and local policies, National Institute for Excellence (NICE) Guidance, voluntary sector, NHS provider and social care provider feedback and, most importantly carers' views and wishes.

NHS England London Region in association with the national NHS England Commitment to Carers Team and ADASS London co-hosted a collaborative learning event on the 12th July 2022. This regional response showcased some exciting work around discharge to access (D2A) and carers which was funded by the national Commitment to Carers Team and also included the latest research from Carers UK and Healthwatch Wandsworth. This was the start of a conversation with carers, health and care organisations and voluntary sector partners across London to improve the carer journey.

Carers UK Report September 2021 - **Carers experience of Hospital Discharge: Discharge to Assess Model**

Healthwatch Wandsworth May 2022 - **HealthWatch Wandsworth Report Carers and Hospital Discharge May 2022**

Four pilot sites funded by the National Commitment to Carers Team presented on their work. Final reports on the wider national programme can be viewed by registering with the **Commitment to Carers Collaboration website**

A second event was held on the 5th October 2022 to launch the process to co-produce a practical resource for health and care staff to support carer friendly hospital discharge.

This toolkit has been informed by both events with a total 375 people engaging in this project.

Glossary of terms

Definition of a carer

The Care Act 2014 defines a carer as an adult, aged 18 or over, who provides, or intends to provide, care for another adult who needs care because of a disability, health condition, frailty, mental ill health, addiction or other health or care needs. It excludes those who provide paid care or do so as voluntary work.

Definition of a Young carer

Young carers are defined as children under 18 with caring responsibilities. Their rights to be assessed come mostly from the Children Act 1989 and the Children and Families Act 2014 although important to note the Care Act 2014 refers to adopting a 'whole family' approach in reference to children and young people caring for an adult.

Definition of a Parent carer – Children and Families Act 2014

A person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility. - Children and Families Act 2014. Whilst the new legislation around hospital discharge applies only to individuals caring for an adult, it is important for hospitals to be mindful of the importance of involving parent carers and recognising their own potential need for support. Parent carers have the right for their needs to be assessed under the Children Act 1989.

What is discharge?

This is a catch-all term used to describe the process for getting a patient, who is in hospital or an intermediate care setting (for example, for a short period of rehabilitation), ready to leave.

Carers' Perspective

This toolkit covers the general principles that apply to all carers including parent carers and young carers. We want carers supported across the whole system, and for carers to be seen as everybody's business.

The caring journey is rarely static and is unique to each carer and family and, as such, no one organisation can deliver on all their care and support needs which is why this toolkit has been developed in line with the **NHS England Commitment to Carers Toolkit**. This helps local partners come together to develop an integrated approach to supporting carers.

To learn more NHS England have produced a short film – **Carers and integrated approach**

By following an integrated approach carers in London should be able to expect to:

- Be identified as a carer as early as possible and be assessed in the context of a whole family approach;
- Have access to high quality information, advice and support that is personalised and which they can trust;
- Be encouraged to recognise their role and rights;
- Have their rights and those of the person/s they care for championed and protected;
- Be informed, respected and included as expert partners in care;
- Be involved in discharge planning from the point of admission;
- Have access to support and training that will enable them to feel confident in their caring role;
- Have choice and control in their caring role;
- Be respected and treated with compassion if they are no longer willing or able to care;
- Have their own needs and wishes as an individual recognised and supported;
- Be advised on who they can contact in an emergency or crisis post discharge;
- Be supported to remain in work, training and/or education;
- Be supported in getting financial advice, including about welfare and benefits;

- Be able to stay healthy and live well themselves, including accessing breaks to support them to maintain their own wellbeing;
- Have meaningful opportunities to have their voices heard, and be empowered to share their lived experience which will influence learning and change; and
- Be socially connected and not isolated.

Why it's important to identify, recognise, value and support carers.

Like everywhere else in the country London runs on its unpaid care. According to the 2011 census there were 687,000 carers including 144,000 young carers. This number is likely to be an underrepresentation of the full caring population in 2022. Without their support our systems would collapse. Carers UK research estimates that the value of their contribution to our London health and care system is estimated at over £13.8billion annually and £132billion nationally and yet carers experience significant health inequalities.

Research evidences that by supporting carers we:

- Reduce hospital admissions and re-admission. In one random control trial 62% of readmissions were associated with the carer.
- Reduce demand on primary care through specialist carer support services.
- Provide better health outcomes for patient and carer.
- Reduce the costs of delays in transfers of care.
- Reduce overall spending on care.

There are rewarding, positive, and beneficial aspects of a caring role, including personal fulfilment, strengthening family ties, and saving family resources but there is now substantial evidence to show that there are many challenges. Many carers are not well prepared for their caring role. Stressors related to providing care can frequently be persistent, uncontrollable, and unpredictable. They impact on many levels including:

- Carers physical and mental wellbeing
- Isolation and loneliness
- Financial hardship
- Wider family roles and responsibilities especially where there may be multiple caring roles or where the patient themselves is the main carer

- Work and employment, including education and life chances for young carers
- Ability to have and sustain a life outside of caring.

The impact of caring on someone's physical and mental health has been well documented. In the Carers UK report '**Carers Health and experiences of primary care**', the charity examined unpaid carers' responses to the 2021 GP Patient Survey. Of the 850,000 responses, nearly 1 in 5, (18%) have some unpaid caring responsibilities. This would suggest there is a large gap between the carers already known to services and those who are not.

When carers are not identified they miss out. **Carers UK Missing Out the Identification Challenge 2016 Report** found that:

- Half of carers (50%) said that missing out on support had an impact on their physical health
- Three quarters of carers (78%) suffered from stress and anxiety as a result of missing out on support
- 3 in 5 carers (61%) said missing out on support put a strain on their relationships with friends and family
- For half of carers (52%) missing out on support impacted negatively on their finances
- 2 in 5 carers (42%) said missing out on support had caused them to give up work to care.

To read the latest research click on this [link](#)

Further research conducted by **Caring Together** showed that on average young carers were caring for 3 years before being identified, but some were caring for over ten years. It also shows who they were identified by - none were identified by hospital staff and only 7% by a GP.

Appendix - Legislative and Policy Context

- Health and Care Act 2022 - Section 91 Hospital Discharge and Community Services - The current version of the government's "**Hospital discharge and community support guidance**" was published on 31 March and updated on 1 July 2022. Unlike recent versions, the guidance is clear about the need to ensure that carers and young carers are identified, kept safe during the discharge process and signposted to sources of help and assessment of their needs. The guidance also now highlights the need to "ensure that no carers are left without adequate support or an assessment of their longer-term needs (if needed)."
- Care Act 2014 - duties to identify and provide information to carers, undertake carers assessments and provide preventative support. The accompanying statutory guidance makes clear that young carers must not be left with inappropriate tasks or levels of caring responsibilities. There is also a provision for assessments for young carers in transition to adulthood.
- Children Act 1989 (as amended by the Children and Families Act 2014) - duties to identify and provide information to young carers and parent carers, undertake young carers needs assessments and parent carers assessments and to provide preventative support. Both the Care Act 2014 and Children Act 1989 include requirements for NHS bodies to cooperate with local authorities, including in relation to their responsibilities to carers and young carers.
- Carers (Recognition and Services) Act 1995 - these provisions also still apply to other carers of disabled children (grandparents, aunts, uncles and adult siblings)
- NHS Long Term Plan – **Carer Objectives**
- NICE Adult Carers Support and Quality Standard (**National Guidance 150**)
- NICE Transition between inpatient hospital settings and community or care home settings for adults with social care needs (**National Guidance 27**)

Acknowledgements

NHS England Commitment to Carers Team

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Nine London region 'Trust Patient & Carer Discharge Projects' were part of over 40 national Trust Discharge projects intended to improve our understanding and develop best practice around involving, listening to and valuing carer voices in hospital discharge processes. This work forms part of our NHS Long Term Plan deliverables.

Lead author:

Debbie Hustings – Carers Lead NHS England London Region

Contributors:

Jen Kenward – Experience of Care Lead, Community, Primary & Integrated Care, Experience of Care Team, NHS England

Dame Philippa Russell DBE – Vice President Carers UK and the Chair of the former Standing Commission on Carers.

Professor Siobhan Gregory – NHS England London Region, Clinical Quality Director

Claudia Brown – Brent Council, Operational Director Adult Services (DASS), Carers Lead London ADASS

Helen Petterson – NHS England London Region, Director of Recovery

Jane Clegg – NHS England London Region, Chief Nurse

Tiffany Adonis French – Brent Council, Head of Service Information and Long-Term Support

Janet Meehan – Partnership and Development Manager, Carers Trust

Sarah Cook – Manager, Healthwatch Wandsworth

Ros Spinks – Patient and Public Involvement Advisor – National Covid 19 Vaccination Programme (NHSE)

Emily Holzhausen – Carers UK, Director of Policy

Bethany Anderson – Communications and Engagement Manager, NHS England - London

John Bangs – Independent Carers Policy Advisor

Paul Carter – NHS England Commitment to Carers Team, Carers Delivery Programme Manager

Virginia Malicdem – Senior Discharge Nurse, Chelsea and Westminster Foundation Trust (NWL),

Yvette Roach-Smith – Head of Integrated Discharge, Chelsea and Westminster Foundation Trust (NWL),

Barbara Sopitan – North Central London System Resilience and Urgent & Emergency Care Lead

Mark Warwick – Enfield Carers Centre

Emma Doyle – Project Manager, Integrated Care Transformation Team, Guys and St Thomas Trust & Kings College London (SEL),

Contributors:

Simon Dickinson – Digital Catalyst

Julie Atkins – Project Lead Carecity Innovation C.I.C

Andy McGowan – Head of Engagement ‘Carers Together’

Andrea Hone – Patient and Carer Experience Nurse, Carers Lead Nurse/Deputy to Patient Experience Lead Nurse, West Hertfordshire Hospital Trust

Ramzi Suleiman – Policy and External Affairs Officer, Carers Trust

Sharon Murray and Amy Manji – Brent Adult Social Care

Sue Ross-Younger – NHS Devon ICB

Paula Tucker – Deputy Chief Nurse, SASH

Charlotte Rowbotham – Patient and Public Participation Lead, SASH

Janice Clark – Carer

Sue Tresman – Independent Carers Lead, Surrey Heartlands

Verity Comley – Programme Manager, NHS England Commitment to Carers Team

Jodie Deards – Carers Lead, NHS England East of England Region

Caroline Cameron – Carers Lead, NHS England South East Region

Steve Shaffelburg – Commissioning Manager, Adult Social Care and Public Health servicing Richmond and Wandsworth Councils

Sigrid Draeger – Carers Lead NHS England NW Region

Briony Sloper – Deputy Director – Health and Care in the Community, NHS England London Region

Andre Lotz – Better Care Fund Manager – London Regional Lead, NHS England London Region

Clare Rachwal – Deputy Head of Service, Market Development and Community Engagement (including Carers and Neurodivergence), Adult Social Care, Portsmouth Council.

Hannah Leask – Senior Commissioning, Adult Social Care & Health, London Borough of Newham

Corinne Moocarme – Enhanced Health in Care Home Lead, NHS England London Region

Dan Heller – Senior Programme Manager

James Townsend – Co-Founder and CEO-Mobilise

Suzanne Bourne – Head of Carers Support Mobilise

Nicky Hyde – Senior Partnership Manager Mobilise

Alison Taylor – CEO - Carers First

London Health and Care in the Community Team

All the London Region Carers Support Services Leads including Carers Trust Networks Partners

And all the carers who took part but who wish to remain anonymous

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