NHS
South West
Yorkshire Partnership
NHS Foundation Trust

Carers' pathway
Information for staff

With **all of us** in mind.

The Trust's carers' pathway is a way of ensuring carers receive the support they need at the right time.

It also helps health care staff identify, recognise and support carers, and helps carers recognise if they are receiving the support they're entitled to.

The carers' pathway has four steps.

Step one

Carer identification: Have you been identified as a carer?

A carer is anyone looking after a family member, partner or friend who needs support due to their illness, frailty, disability, mental health condition or addiction and cannot cope without their support. This is an unpaid role.

The carer should:

- Be identified at the earliest possible stage and their details recorded on the relevant clinical system, usually this is SystmOne.
- Confirm that they are willing and able to care. Any children in the household who might take on a caring role should also be identified, as well as any parent/carer who provides care for a disabled child for whom the person has parental responsibility.

This is subject to the service user or patient giving their consent.

If there are multiple carers, ask them to agree who will be the main point of contact for them all, however it is important to remember that all have rights to support and assessment.

If consent is not provided by the service user or patient, carers still have their own rights to advice and support, and you should record carer status on their own clinical record (if the carer gives their consent).

Identifying that somebody is a carer is the first step to providing them with the support they need to maintain their own mental and physical health and wellbeing.

A main barrier to accessing support for carers is that they are often not identified; they may not recognise themselves as carers. They may not be aware of the changing nature of their relationship with the person they care for - becoming a carer can be a gradual process, and they might see this as part of their role, for example as a daughter, son, partner or as a good neighbour or friend. As such, the term carer does not always resonate.

We can support people to recognise their caring role and understand that the term 'carer' is valued, recognised in law and provides access to a range of advice, information and support.

Similarly, many carers are not identified by health and care staff. These are commonly known as 'under-represented carers' as they do not access the support available, often because they do not know it is there. Young carers may not be identified as they are often not seen by health and social care professionals, yet there is estimated 175,000 young carers in Britain.

Top tips:

- Language is key - instead of asking "Do you have a carer?" or "Are you a carer?" try asking "Is there anyone who helps to support you when you need help at home?" or "Do you support the patient at home, and would they be able to manage without your support?".
- Do not confuse a person's next of kin with being a carer. They may be completely different.
- The patient or service user might be a carer, so it is important to know if the person they care for is receiving care during their absence.
- To engage with young carers, attend home visits out of school hours.

Step two

Carer recognition: Has the carer been recognised? Do they have a point of contact? Do they have a carer passport?

The carer should be:

- **Welcomed** and given **advice and information.**
- **Given the name of a member of staff who they can speak to when needed.**
- **Given a carers' passport**. (this is documented on SystmOne).
- **Provided with contact details for carer champions (carerschampions@swyt.nhs.uk), carers project management officers/carer leads (gillian.cowell1@swyt.nhs.uk) and additional support if required.** (find out more on the carer pages on the intranet).

Carers can struggle for recognition and support. Involving carers in decision-making and recognising their role as expert partners in care benefits service users, patients and carers alike. Carers have a wealth of knowledge about the person they care for and are often key to helping understand the person's needs and preferences, which can help inform development of the care plan, safety plan, and risk assessments/management plan.

We know from research that many carers feel both invisible and ignored, especially young carers who may often be seen as a child, even though they may be the primary carer at home. When a carer's value is recognised and respected as a core member of the team around the person they care for, everyone wins.

Providing there is consent from the person, and their wishes remain central, carers should be supported to actively participate in decision making and care planning for the person they care for.

Where consent is not given, practitioners should routinely and frequently confirm with service users where and how they wish their family, friends, or carers to be involved in their care, and confirm details around what they are willing to share and what they specifically want to remain private.

This should be a continual process of revisiting consent to share and open channels of communication should be maintained with carers where consent is not explicit.

Sharing information is a crucial consideration in situations of suicide risk. You can read useful information on this at:

https://www.mind.org.uk/information-support/helping-someone-else/supporting-someone-who-feels-suicidal/about-suicidal-feelings/

https://swyt.sharepoint.com/sites/Carers

What information is confidential?

People have varying opinions on what they consider to be sensitive and confidential. An example of the golden standard to involving carers is where a service user is first seen on their own, then the carer alone (with the service user's agreement) and finally both together, where practicable and appropriate. In this way, care teams can understand both the service user and the carer's wishes, learn what each considers to be sensitive and confidential and what they are willing to share.

Where language barriers make effective communication difficult, staff should make every effort to clearly understand individual needs, including using an interpreter or getting advice if necessary. Staff must be mindful of the way cultural difference and attitude may affect the role of carers and their understanding about confidentiality. It is possible that the service user and the carer might have differing expectations. Staff should be open and informative but sensitive where individual autonomy and freedom of choice may not be part of the carer's values. In all cases where the carer's role is critical to the recovery of the service user, the principles set out in this leaflet will guide practice regardless of culture, religion, social status, disability, sexuality or gender.

As an area of good practice, the team will:

- Discuss with the service user what particular information they wish to withhold, if any.
- Explain they are bound by law and professional codes of conduct and have a duty of confidentiality to their patients.
- Explain to the carer they have the same right to confidentiality as a service user/patient to any information they wish to discuss.
- Discuss the importance of confidentiality with the carer

an early stage and that views on information sharing are recorded.

- Explain to the carer what information can be shared and if information cannot be shared, what the reasons are for this.
- Explain to the carer If the service user doesn't give permission, confidential information can only be disclosed in exceptional situations, such as where the service user's, or others' health and wellbeing is under serious risk, or where there is a public interest or legal reason for disclosure without consent.

Top tips:

- Make an appointment early in the person's care so that carers can speak with a member of staff and ensure the initial assessment and plan of care is balanced, correct, and considers all factors. This is especially important when the patient is a child or when they lack capacity to make an informed specific decision. Find out more about the Mental Capacity Act on the intranet: https://swyt.sharepoint.com/sites/Intranet/mental-health-law/Pages/Mental-Capacity-Act.aspx
- If the person has not provided consent, you can still provide carers with general information around carer support which is not associated with the person's direct care, e.g. Information about the condition, symptoms and behaviour it may cause; advice on managing these, particularly in a crisis situation; background information on medication and possible side-effects, and details of the care coordinator/key worker or team.
- You should always listen to the carer/family member, their views matter. The information they provide us with can help better inform our plan of care, manage risk, and support recovery.

Step three

Assessment and support: Does the carer know how and where to get a carers assessment? Has the carer been signposted or provided with carer support?

The carer should be:

- **Informed they have the right to a statutory carer's assessment of their own needs, and why this is beneficial.**
- **Referred to the local carers' support service or given information on how to self-refer.**
- **Given the practical skills and training to allow them to care.**
- **Encouraged to share the support needs of the family and children.**

Although the legal duties to assess carers support are the responsibility of local authorities, there are many ways in which 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.

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

Staff can also make sure that parents know about rights for young carers. A young carer's assessment should be part of the whole family approach. Local authorities have a duty to assess 'on the appearance of need' (i.e. without a 'request' having to be made, although this must be provided if the young carer or the parent requests one). 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 alongside any education, training, work or recreational activities the young carer is/wishes to participate in.

Top tip:

- At any time in the care process, if consent has been provided by the carer, signpost people to the relevant carer support agency who will complete their own assessment to meet the needs of the carer.

Step four

Transition: Has the carers perspective been given consideration?

Carers should be supported when moving through services to make sure they have a safe transition, as you would with a patient or service user.

Staff should discuss with the service user/patient how they can manage their condition after discharge, making sure carers are involved in this process. This should include support and education, including coaching, if needed. This should be available for carers as well as for patients and service users.

Provide any medication and equipment needed at home, as well as instructions and information about how to use them. You should also give the details of who to contact following discharge.

Top tips

- Support carers at the point of discharge, provide them with information and support to potentially prevent the service user/patient being readmitted to hospital. Refer to their carers' passport to make a contingency plan for a scenario where they will be unable to care. Refer to the passport for information about how to access further support locally.
- Carers have the opportunity to see a professional on their own and the right to their own confidentiality when talking to professionals.

Advance decisions

A person who is **over 18 years old** and **has capacity** can make decisions to **refuse their treatment** for a time in the future when unable to do so. **This is legally binding.**

Advance decision to refuse life sustaining treatment

Where the advance decision relates to the refusal of life sustaining treatment this must be in writing and signed by the person and one other person. Family or friends involved in these discussions can sign the form. (**Refusal of treatment cannot include attempts for the person to end their own life, or refuse basic care including food and fluids**).

Advance statements

A person can provide information about their views, wishes and preferences and what is important to them. Statements must be taken into consideration in the future when the person lacks capacity to make a range of decisions.

General information

A person who wishes to make an advance decision or statement must have capacity to do so.

With the person's consent, their family, friends, and carers should be included in discussions about their advance decisions and statements.

This means that those who know the person well can ensure what is important to the person can be fully included in decision making.

In the discussions about advance decisions and statements staff should emphasise that it is the persons duty to share their advance decision and statements so that care and treatment can be provided in accordance with the person's wishes.

If the person needs care and treatment from another organisation, family, friends and carers who have a copy of the advance decisions and statements will need to provide a copy of them to the treating team.

Where there is an emergency the health care professional does not have to wait to see any advance decision or statement but may treat the person.

When a person is under the Mental Health Act in hospital the advance decision cannot prevent the treatment for the person's mental health but should be considered by the treating team.

Advance decisions and statements should be revisited to confirm that they reflect the person's wishes, health and care needs.

Each organisation will have its own policy and processes in respect of advance decisions and statements. The law around advance decisions and statements, is complex and is applied on a case by case basis.

Checklist for involvement:

Have you completed the questionnaire on SystmOne If not please complete.

Additional support and links

For further support, contact carers project manager Gillian Cowell
gillian.cowell1@swyt.nhs.uk.

The Trust's aims and ambitions for suicide prevention
https://swyt.sharepoint.com/sites/Intranet/Suicideprevention/Pages/default.aspx

Good psychiatric practice: Confidentiality and information sharing
https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2017-college-reports/good-psychiatric-practice-confidentiality-and-information-sharing-2nd-edition-cr209-nov-2017

Jargon buster
https://www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/

Notes

Notes

If you require a copy of this information in any other format or language please contact your healthcare worker at the Trust.

إذا كنت تحتاج إلى نسخة من هذه المعلومات بأي صغة أو لغة أخرى، فيرجى الاتصال بأخصائي الرعاية الصحية الخاص بك في أمانة الصحة الوطنية (Arabic)

Pokud požadujete kopii těchto informací v jakémkoli jiném formátu nebo jazyce, kontaktujte svého zdravotnického pracovníka z Trust. (Czech)

چنانچه اگر شما به یک نسخه از این اطلاعات در هر قالب یا زبان دیگری نیاز دارید، لطفاً با کارمند مراقب بهداشت خود در بنیاد (Trust) تماس بگیرید. (Farsi)

Si vous avez besoin d'une copie de ces informations dans un autre format ou dans une autre langue, veuillez contacter votre professionnel de santé au service national des soins médicaux (NHS). (French)

Ja jums ir nepieciešama šīs informācijas kopija jebkādā citā formātā vai valodā, lūdzu, sazinieties ar savu Trasta veselības aprūpes darbinieku. (Latvian)

如果您需要以任何其他格式或语言版本获取此信息，请与您的国民健康服务医疗保健工作者联系。(Mandarin)

Jeśli potrzebuje Pan(i) kopii tych informacji w innym formacie lub języku, prosimy o kontakt z pracownikiem służby zdrowia. (Polish)

ਜੇ ਤੁਹਾਨੂੰ ਕਿਸੇ ਹੋਰ ਫਾਰਮੈਟ ਜਾਂ ਭਾਸ਼ਾ ਵਿਚ ਇਸ ਜਾਣਕਾਰੀ ਦੀ ਇਕ ਕਾਪੀ ਦੀ ਜ਼ਰੂਰਤ ਹੈ ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਟਰੱਸਟ ਵਿਚ ਆਪਣੇ ਸਿਹਤ ਸੰਭਾਲ ਕਰਮਚਾਰੀ ਨਾਲ ਸੰਪਰਕ ਕਰੋ. (Punjabi)

اگرآپ کوان معلومات کی ایک نقل کسی اورشکل یا زُبان میں چاہیے تو برائے مہربانی ٹرسٹ پراپنے ہیلتھ کیئر ورکرسے رابطہ کریں۔ (Urdu)