

PERSONALISATION, THE NHS AND YOUNG CARERS



**Young Carers
Alliance**

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INTRODUCTION

THIS PAPER FROM THE YOUNG CARERS ALLIANCE IS LOOKING TO PROMOTE RECOGNITION OF WHOLE FAMILY APPROACHES AND THE NEEDS OF YOUNG CARERS THROUGHOUT NHS ENGLAND'S PERSONALISATION AGENDA AND TO HELP INFORM THE WORK OF INTEGRATED CARE BOARDS.

Personalised care is based on “what matters to people and their individual strengths and needs”. NHS England have developed a comprehensive model for universal personalised care which has been embedded in the NHS Long Term Plan and more details of this approach can be seen on the NHS website. <https://www.longtermplan.nhs.uk/areas-of-work/personalised-care/>

These policies have considerable potential to improve patient care but to fully achieve this potential, the needs of carers of all ages also need proper recognition. For young carers, we see this focusing on the requirements for:

- Improved identification of young carers by health professionals
- Signposting young carers and their families to support



WHO ARE YOUNG CARERS?

By definition, a young carer is someone under the age of 18 who looks after a family member or friend who has a physical or mental health condition, or misuses drugs or alcohol. This may be for parents but could also include brothers, sisters or elderly relatives too.

Young carers services often work with those as young as five years old but there could be child carers who are even younger. There are an estimated 800,000 young carers in the UK: typically 2 to 3 in any classroom.

YOUNG CARERS' RIGHTS

While the NHS does not have a duty to undertake young carers needs assessments, when undertaking their own care assessments, they do have obligations to identify children who may be impacted and refer for assessment and support as necessary. The requirement for this was already in place because of statutory requirements for NHS bodies to cooperate with councils for both the Children Act 1989 and Care Act 2014. This is reinforced by similar duties to cooperate in the Health Care Act 2006.

This obligation has recently been further reinforced by the inclusion of young carers in the Health and Care Act 2022 and accompanying statutory hospital discharge guidance. The provisions of these Acts are reinforced and complemented by a range of other policy and guidance.

Despite all this, the experiences of carers suggest that these requirements relating to carers and young carers are not well understood by many health staff. This is why there seems to be a strong case for NHS England to produce guidelines to help embed a whole family approach and recognition of young carers. Alternatively, "sector led guidance" in this area may be needed. More details of the relevant legislation, policy and guidance are outlined in Annex 1 below.

UNIVERSAL PERSONALISED CARE

NHS England have developed a comprehensive model for universal personalised care and the principles of this have been embedded in the NHS Long Term plan. There are six components within this:

- Patient Choice
- Shared Decision Making
- Supported self-management
- Social Prescribing
- Personalised Care and Support Planning
- Personal Health Budgets

PATIENT CHOICE

There is considerable emphasis placed on patient choice, which seems unarguably the right thing. This is about, where care is provided and also when there are options available, how health care is provided. This applies to all patients including carers. Depending on a young carer's age and maturity, it may be appropriate to discuss young carers' health needs and choices with themselves as well as their parents.

However, health practitioners also need to remember that carers have a right to choose whether or not to take on caring responsibilities. A patient cannot simply choose for a friend, partner or relative to care without their consent. In the case of young carers, even if a child or young person appears to agree to care, it is essential to consider whether the tasks or level of caring responsibilities are age appropriate. When considering this, the advice of a young carers support worker or children's social worker is likely to be helpful.

SHARED DECISION MAKING

It is important that children and young people are engaged in the process and it is essential to try and help them understand the condition of the patient/person they care for. A lack of information about conditions will often lead to young carers either trying to find their own information online or creating their own internal narrative. The discussion and information need to be conveyed in an age-appropriate manner. However, while young carers should be consulted, they should not be asked to make decisions in a manner that implies a responsibility that is simply not age appropriate. Again, the advice of a young carers support worker or children's social worker is likely to be helpful.

SUPPORTED SELF-MANAGEMENT

The approach of supported self-management for children needs careful thought. Depending on their age and maturity, it can be beneficial to support young carers in understanding their own health needs, as well as those they are supporting. Young carers do also though, need to be helped to think about a life outside of caring, and to ensure their future life chances are not being restricted by caring responsibilities.

SOCIAL PRESCRIBING

Social prescribing is an approach that connects people to activities, groups, and services in their community to meet the practical, social and emotional needs that affect their health and wellbeing. It provides a way for local agencies to refer people to link workers who give people time, focusing on 'what matters to me' and taking a holistic approach to their health and wellbeing.

There are two main aspects of social prescribing that particularly relate to young carers:

- Where children are being supported, it is essential for those professionals involved to be young carer aware. Statistically, young carers form a significant portion of the cohort of "vulnerable children" that social prescribing is targeted at. This, of course, includes young carers looking after brothers or sisters.
- Where an adult is supported, it is important to adopt a "whole family approach" and be aware of the circumstances of family members and any other people involved in caring. This is essential if link workers are to get the whole story. There must be provision to identify carers and young carers and to make appropriate referrals for support.
- If the young carer or their parents consent, then ensure they are registered as a carer within Primary Care using the appropriate SNOMED code.

PERSONALISED CARE AND SUPPORT PLANNING

A personalised care and support planning conversation with an adult is also an important opportunity to identify any young carers. Where young carers are identified, the appropriateness of the level of caring responsibility they are taking on should be considered and addressed. (eg. by referring for a young carers needs assessment or to a young carers support service). The young carer should be given an opportunity to have a separate conversation about their own needs, including what's working or not working; what's important to them for their own health and wellbeing and how they can have a life outside of their caring role. This could result in a personal wellbeing plan of their own.

PERSONAL HEALTH BUDGET

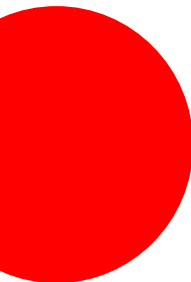
Having identified what is important to the young carer for their own health and wellbeing, it may be that a small amount of money in the form of a personal health budget could help support these needs. This should be thought about alongside a range of support options, including information and advice, social prescribing and changes in arrangements and increased support for the 'cared for' person that reduce the demands on the young carer and enable them to have a life outside caring.

Sometimes too, through being mindful of a young carers needs, small changes in the personal health budget arrangements for the person they care for can be made that impact positively on the young carer's health and wellbeing.

OVERARCHING REQUIREMENTS

The NHS is under a number of legal obligations to consider the needs of carers and young carers – including when undertaking a care and support needs assessments. These assessments can include those for Personal Health Budgets, Continuing Health Care, under the Community Mental Health Framework, for Hospital Discharge or for Wheelchairs. These requirements can be summarised as:


- Identifying all family members who are likely to be involved, including any children or young people in the household.
- Determining whether they are young carers or are likely to become so at the point of a hospital discharge. Practitioners need to be aware that not all will identify as young carers or even know that the term applies to them. A proactive approach using age appropriate language is therefore necessary. (Simply asking “are you a young carer?” does not work, so investigate who does what in the household. This can better help find out whether a child or young person is caring)
- Giving young carers age-appropriate information about both the assessment or discharge process and support available to young carers. This should include information about young carers services and also how to access young carers needs assessments or transition assessments. Young carers should also know who they can contact if they have any concerns relating to the person they care for.
- Considering the views and needs of any carers or young carers where a hospital discharge date is being decided .

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- Not assuming that relatives are willing or able to take on the role of carers or that carers will provide all the support needed. Young carers must not be left with inappropriate forms or levels of caring responsibilities
 - Arranging where necessary, with the local authority for young carers needs assessments or transition assessments to be undertaken and consideration given to a referral to local young carers support services
 - Young carers must not be left in a position where they are undertaking excessive levels of caring responsibilities

The legislation and policies that underlie these requirements are described in more detail in Annex1 below.

INFORMATION AND TRAINING FOR STAFF

Local systems need to ensure that staff involved in assessments (including hospital discharge processes):

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- Understand who carers and young carers are and the importance of their role and insights,
 - Being aware of the importance of avoiding young carers being left with inappropriate caring tasks or inappropriate levels of caring
 - Have information to give to carers and young carers explaining support available and how to access carers assessments and young carers needs assessments
 - Understand how and who to refer or signpost to for support or assessment

A CALL FOR ACTION

This paper is being presented to NHS England with a view to further developing personalised care in relation to young carers and their families. We hope to work with NHS England and other partners to develop guidance for Integrated Care Boards.

We also hope this paper will assist local discussions with ICBs around recognition and support for young carers. For example, this should include ensuring proper recognition of young carers within social prescribing services, as well as for Continuing Health Care and assessments for personal health budgets.

ANNEX 1: YOUNG CARERS RIGHTS; LEGISLATION AND POLICY

CARE ACT 2014 - includes duties to identify and provide information to carers of adults, undertake carers assessments transitions assessments for young carers and parent carers, and provide preventative support. The accompanying statutory guidance makes clear that young carers must not be left with inappropriate 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) - this contains 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.

THE NHS ACT 2006 section 72 requires NHS bodies to co-operate with each other and section 82 requires that this also extend to working with local authorities 'in order to secure and advance the health and welfare of the people of England and Wales'. Taken together with the duties to cooperate in the Care Act and Children Act, there can be no doubt that NHS bodies have a duty to cooperate in relation to carers of all ages.

CARERS (RECOGNITION AND SERVICES) ACT 1995 - the provisions of identification, provision of information and assessment also still apply to other carers of disabled children including grandparents, aunts, uncles, and adult siblings.

THE HEALTH AND CARE ACT 2022

The provisions of the act include:

- A duty on NHS England to consult carers (including young carers)
- A duty on Integrated Care Boards to consult carers (including young carers); both around planning and commissioning and also around services relating to the patient for prevention, treatment and diagnosis
- Powers for the Care Quality Commission to assess the performance of local authorities which will include their duties to carers
- Duty on NHS hospital trusts to ensure that unpaid carers of all ages are involved as soon as feasible when plans for the patient's discharge are being made.
- Provision for statutory Hospital Discharge and Community Support Guidance which has a higher status and is more directive than most other NHS guidance

The legislation also makes clear that, as the NHS is an all-age service, the term carer includes young carers.

THE CARE PROGRAMME APPROACH/ COMMUNITY MENTAL HEALTH FRAMEWORK.

The NHS England position statement (1 March 2022) reaffirmed that the Care Programme Approach (CPA) has been replaced by the national Community Mental Health Framework. One of the 5 core principles for implementing new arrangements is “meaningful engagement with families and carers.” The document also confirms that the new arrangements must be “Care Act compliant”. This therefore means that there is a requirement for young carers to be identified and protected from having to undertake inappropriate levels of caring. There is also an obligation to respond to the needs of young carers in transition to adulthood. Where a young appears to need information or support they should be referred to a local young carers service for support or where appropriate referred to children's services for a young carer needs assessment.

NHS CONTINUING CARE

The guidance specifies that:

- NHS bodies have a responsibility to work in partnership with carers and young carers so that they can be better supported with their caring role. Healthcare professionals should be proactive in identifying carers and be sensitive to the level of support they need and desire.
- This approach should be reflected in any checklist and/or full assessment of eligibility for NHS Continuing Healthcare with carers and family members involved where appropriate.
- Carers and young carers must be told of their right to carers assessments and young carers needs assessments and referrals for these made as appropriate.
- The ICB may need to provide additional support to care for the individual whilst the carer(s) has a break from his or her caring responsibilities.

NHS CONSTITUTION

The NHS Constitution (2015) to which every NHS body in England must have regard - (National Health Services Act 2006 section 14P) commits the NHS to 'work in partnership with patients and carers' and to ensure that its services are 'coordinated around and tailored to, the needs and preferences of patients, their families, and their carers'. The NHS is an all-age service and therefore the term carer applies to carers of all ages.

The constitution lists seven key principles to 'guide the NHS in all it does', of which Principle Four recognises that: "Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment"

NHS LONG TERM PLAN

The NHS Long Term Plan said “we need to prevent young carers struggling on their own with difficult and multiple challenges”. It committed to roll out ‘top tips’ for general practice, developed by young carers. It also committed to provide young carers with better access to preventive health and social prescribing and timely referral to local support services.

NHS ENGLAND CARERS TOOLKIT

NHS England and its partners have developed a toolkit to help health and social care organisations work together in identifying, assessing, and supporting the wellbeing of carers and their families.

This toolkit covers new duties on NHS organisations brought about by the Care Act 2014 and the Children and Families Act 2014, and includes numerous examples of positive practice that are already making a difference to carers.

The toolkit also includes a template Memorandum of Understanding (MOU) that local partners can use to help them work together in supporting carers of all ages. The template MOU includes support for young carers as a key priority.

