

Young Carers – A health perspective

The event will start at 10am

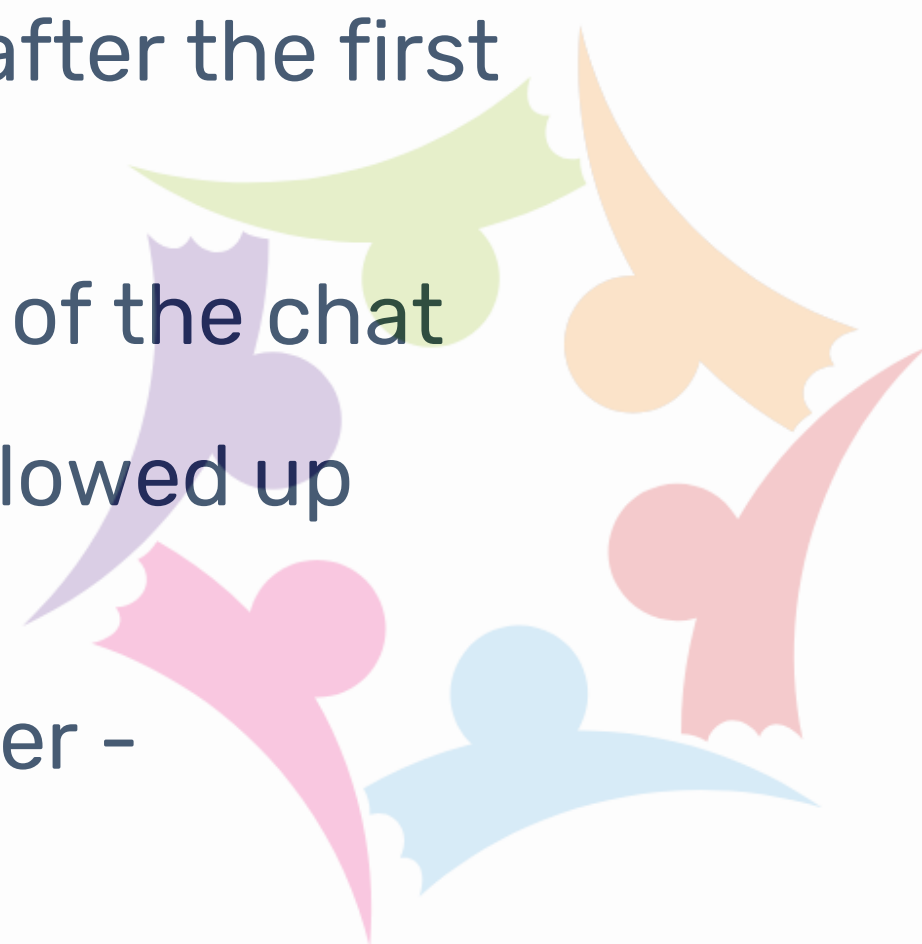
@YCAAlliance

@CarersTrust



Welcome and housekeeping

- Ensure microphones are on mute
- We will be recording the session after the first item
- Introduce yourself and make use of the chat
- Unanswered questions will be followed up after the event
- Join in the conversation on Twitter - @YCAAlliance @CarersTrust



Setting the scene

- 44% of young carers/young adult carers report 'always' or 'usually' feeling stressed because of their caring role. Feelings of stress were particularly highlighted by female young carers/young adult carers (47% vs 37% of males)
- 38% 'always' or 'usually' feel worried because of their role
- More than 1 in 4 young carers/young adult carers say they 'never' or 'not often' feel they get enough sleep
- Over one third (37%) of young carers and young adult carers said the NHS did not understand their needs as an unpaid carer either 'very well' or 'at all'

"I tend to turn my emotions off while being zoned into my caring role. It's when I take a step back that things spiral with all the things I've kept in."



Setting the scene

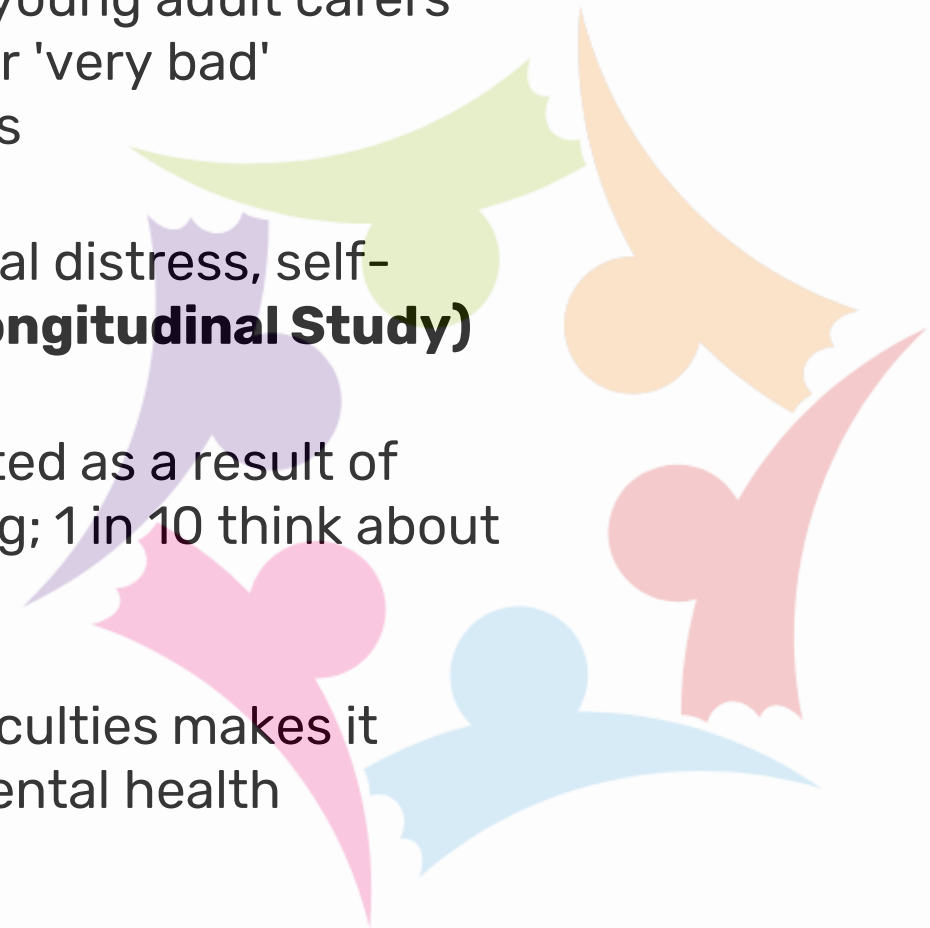
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Young carers in numbers

- GP Patient Survey - higher prevalence of long-term health conditions amongst carers aged 16-24 (43%) than their peers (29%).
- The 2021 Census also showed how young carers and young adult carers were more likely to report their health as either 'bad' or 'very bad' compared to their peers without caring responsibilities
- Young carers more likely to report severe psychological distress, self-harm and make attempts on their own life (**COSMO Longitudinal Study**)
- **ME-WE study** - 56% said mental health had deteriorated as a result of caring responsibilities; 3 in 10 think about self-harming; 1 in 10 think about harming others (including person they care for)
- **NHS Digital** - having a parent with mental health difficulties makes it three times more likely a child will go on to develop mental health problems themselves



Setting the scene



➤ Major Conditions Strategy

1. Cancers
2. Cardiovascular disease (including stroke & diabetes)
3. Chronic respiratory disease
4. Dementia
5. Mental ill health
6. Musculoskeletal disorders (MSK)

➤ 5 priority areas:

1. Re-balancing the health and care system, over time, towards a personalised approach to prevention through the management of risk factors
2. Embedding early diagnosis and treatment delivery in the community
3. Managing multiple conditions effectively - including embedding generalist and specialist skills within teams, organisations and individual clinicians
4. Seeking much closer alignment and integration between physical and mental health services
5. Shaping services and support around the lives of people, giving them greater choice and control where they need and want it and real clarity about their choices and next steps in their care

- Across all 5 of these priority areas, DHSC will work to reduce inequalities in health outcomes, so the community you live in does not make it more likely you will experience ill health.



Setting the scene

- **Health and Care Act 2022**
 - Duties on Integrated Care Boards
 - Duties in relation to hospital discharge
 - CQC Assurance in relation to Integrated Care Boards
- **Core20PLUS5**
 - Core20PLUS5 is a national NHS England approach to support the reduction of health inequalities at both national and system level.
Core20 = The most deprived 20% of the population as identified by the national Index of Multiple deprivation (link to social determinants of health)
PLUS = Particular population groups who need to be considered
 - There is a version for adults and a version for young carers
 - The approach defines a target population cohort and identifies '5' focus clinical areas requiring accelerated improvement.
 - For CYP, young carers are specifically mentioned in the 'plus 5'
 - NHS England will be developing a handbook to support Core20PLUS5 implementation.



Setting the scene



NHS England

- Where next for the long-term plan/Commitment to Carers programme?
- Work with DfE around identification of young carers



DHSC Accelerating Reform Funding

- Funding allocated through adult social care, but expectation to work with the NHS 'and other partners'
- Non-competitive process
- **At least** one project must be related to carers

Priority 4 = Ways to support unpaid carers to have breaks which are tailored to their needs

Priority 7 = Ways to conduct effective carer's assessments with a focus on measuring outcomes and collaboration

Priority 8 = Services that reach out to, and involve, unpaid carers through the discharge process

Priority 11 = ways to better identify unpaid carers in local areas

Priority 12 - Ways to encourage people to recognise themselves as carers and promote access to carer services



Young Carers' Legal Rights and the NHS



John Bangs OBE

Independent Carers Policy Advisor

Retired Surrey County Council officer who worked for 26 years to improve the lives of unpaid carers and is currently a London carer

Young Carers and Hospital Discharge

28th November 2023



Carers and Hospital Discharge toolkit

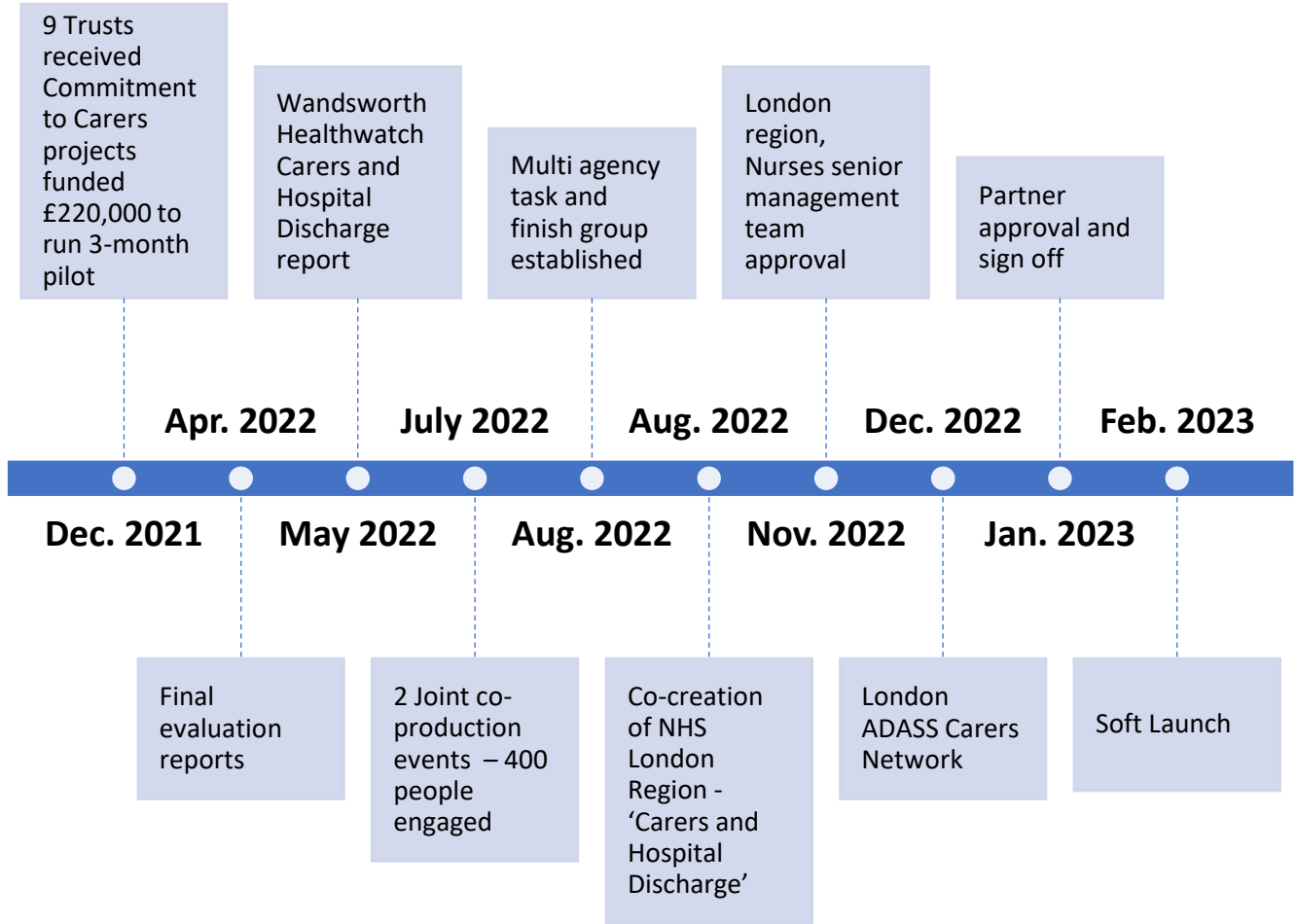
Recognising, valuing and involving unpaid carers throughout the hospital discharge journey.



A collaborative journey



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.



Working with young carers in health? Some thoughts...

What helps

- Overall Young Carer Strategy (Either stand alone or embedded in all ages strategy) and how this connects to Health and Health care providers
- Clear accountability
- Overall Young Carers Lead/Champion in all health settings
- Young Carers Pathway
- Young Carer Awareness Training (YC Rights, What services are available and referral pathways)
- Making Young Carers part of everyone's Job descriptions
- Senior management creating space for staff to work with young carers
- Tech - Health systems systematically collecting young carer data
- Using National Carer Events to raise awareness. Young Carers Pledge
- Clear Guidance around parental consent and Fraser guidance (Gillick Competency)
- Pro-active action taken to ID young carers through assessment procedures
- Using Young Carer Stories and Data to improve Young Carer Experience
- Working alongside Young Carer Services and forums to co-produce services and resources
- Personalised approach

What hinders

- No clear vision or accountability
- No Young Carer Pathway
- No staff training
- Young Carers not part of health Job descriptions
- Managing workload
- Lack of staff skills and capabilities
- Lack of awareness of YC rights
- Parental consent
- Lack of awareness of what support is available in the community
- Lack of visibility in health setting.
- Systems and procedures young carer blind so lack of staff prompts to identify and record young carer data
- Lack of young carers data in settings other than primary care
- Workforce capacity for School Nursing and Health Visitor service
- Over reliance on safeguarding process
- Culture.....

Young Carers Roundtable

Improving identification and support within health settings

Emerging Themes

Systematic approach – Where does responsibility sit for young carers in a system?

Accountability - Who leads on Young Carers work at system level and within NHS Provider Trusts?

Performance – Who monitors young carers identification and support work? Where does this get reported to?

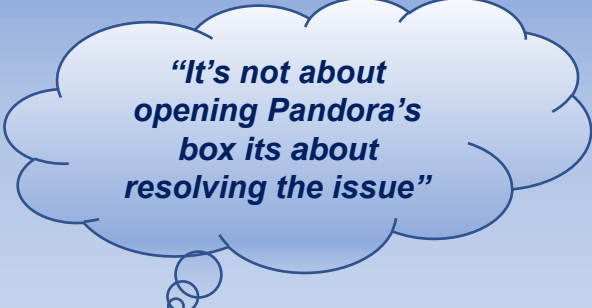
Operational – How are young carers counted in health care systems? How do we measure how the data is being used to better support young carers?

Culture – How do health staff adopt a whole family approach? If they identify an adult carer does that lead to them asking about children who might be caring?

Empowerment – Are health staff given the right skills and training to support young carers? They don't need to be experts on young carers but do they know how to identify and refer to support?

Permission – Do the executive and line managers prioritise this work?

Safeguard - How do we safeguard children from excessive and inappropriate caring?



“It's not about opening Pandora's box its about resolving the issue”

Big ideas

National Standard –

- NICE guidance Young Carers Support (Identifying and supporting child within a Whole family approach)
- Refreshed No Wrong Doors MOU to be developed and to be inclusive of health

Identification Tools –

- Professionals script for conversation openers – *“Is there illness or disability in your family?”*
- Young Carers Pathway.... But not all leading to safeguarding
- Young Carers Service... seek consent to register them with GP using relevant SNOMED code
- National Young Carers ID card and potential to link to NHS App

Recognition - Recognising carers and young carers through 'Equalities' work, CORE20plus5 for Children and young people & staff training

Support - Have a pro-active health offer for young carers

Commissioning – Ensure commissioners are working with health, VCFSE and Young Carers

Operational - Integrating young carers into operational work including IT systems

Carers Pathway

- 1 Identification
- 2 Welcome and recognition
- 3 Assessment and support
- 4 Involvement
- 5 Transition

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.



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, either seeing caring as an extension of their family role, or as a good neighbour or friend. As both the care recipient and those involved with them, supporting friends and family to recognise their caring role and that the care recipient has the responsibility to see and provide 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. Initially, many carers are not identified to health or social care professionals. These are commonly termed 'unseen' or 'unregistered' carers. They do not access the support available, either because they do not know it is there, or 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/work.

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 'unseen' or 'unregistered' carers to describe a care worker or as the person who is recruited as 'lead' or 'key' contact with support services.

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

It is 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:

- reasons for admission
- how they might need to be discharged
- care options and treatment they can expect when they are expected to leave the hospital or any special arrangements to support carers, for example the hospital's Patient Advice and Liaison Service (PALS). If the hospital has a care champion or dedicated carer's space, if a care champion scheme is in operation, and what other built-in options for hospital or parking charges, concessions, access to staff, services 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 that is not available, the options for transport home when the person is discharged from hospital, and the importance of discharge from London specialist hospitals, where the absence home may be considerable.
- care and treatment after discharge.

Carers can struggle for recognition and support needs not with local authorities, but with many other agencies in which health staff can support the process. A key issue is making sure carers know they have a right to an assessment and how to be heard on it. Staff can also ensure that patients know about rights for young carers.

Carers are often confused with how to care and may need support in managing the practical side of their care. Staff should not only help them to use the network of professionals to help identify health goals and seek to transfer skills and knowledge to carers when discharge is planned to care.

For example, carers have 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 relating to the care of their carer
- personal care
- contracts for management including welfare
- managing behaviour that challenges
- digital and specialist 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 advice for self-funders and when the patient meets eligibility criteria for information on NHS funded and contributory health care funding.

For many carers, a period of hospitalisation provides the first real break. They have had not only a break in their caring role, but also a chance to discuss their caring role with the discharge coordinator around the caring arrangements and the support that will be available to use this time to have a much needed break. Sometimes carers may not be permitted to do this and be told, as rarely as possible, that they need to have a break and that the hospital staff can help to take care

Step Two Welcome and recognition



Carers can struggle for recognition and support needs not with local authorities, but with many other agencies in which health staff can support the process. A key issue is making sure carers know they have a right to an assessment and how to be heard on it. Staff can also ensure that patients know about rights for young carers.

Carers are often the only part of the care team and are the care plan that carers consent to. It is not understood and most carers' needs are not going to be achieved if the outcomes are not met.

Following a systematic review study conducted by American Association of Retired Persons (AARP) where they compared discharge planning in hospital care transitions with those where the carers had been registered, these were associated with a 20% reduction in hospital readmission.

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 can struggle to exercise their rights if they receive unclear advice.

Information for carers should be:

- up-to-date, regularly reviewed and meet the NHS Accessibility Information Standard
- clearly worded, clearly presented and free of jargon
- comprehensive, set down in manageable chunks of information which use visual aids or graphics
- culturally sensitive
- respecting carers' rights and how to access social and community support for carers
- providing useful contact numbers of information and support both to the local carers' support service.

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 designated member of the MDT should arrange home care. This should identify professionals from primary care, community health, social care, housing and the voluntary sector and call care staff who will provide support when the patient is discharged and meet their needs 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 professionals as well as discharge planning staff. This includes housing adaptations. Ensure that any specialist specialist equipment and support on place at the point of discharge. This should involve the carer and equipment and support on place at the point of discharge. This should involve the carer and equipment and support on place at the point of discharge. This should involve the carer and equipment and support on place at the point of discharge.

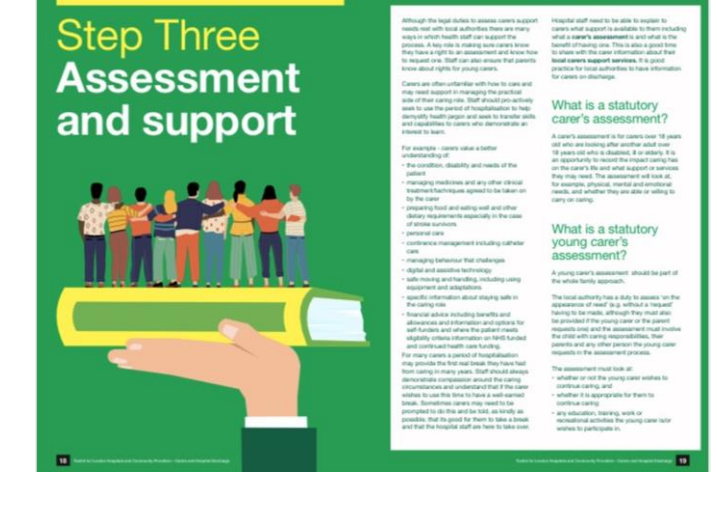
Once agreement for discharge is complete, the discharge coordinator should arrange the plan for ongoing treatment and support for the carer to ensure that the patient has the support they need to manage their care at home.

Staff should discuss with the person how they can support their condition after their discharge from hospital. Provide physical and emotional support, including information on how to access services for carers as well as for patients using services.

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Step Three Assessment and support



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, or elderly. It is an opportunity to assess the impact of caring 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 'in the circumstances of need' (i.e. without a risk of harm) to be made, although they must also be provided for the young carer in the parent's needs and the assessment must involve the other adults with responsibilities, their parents and any other person the young carer identifies in the assessment process.

The assessment must look at:

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

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Step Four Involvement



When consent has been provided, staff and carers working together in equal partnership with the patient's input their collective knowledge and expertise can be used to deliver individual care and support plans to help support necessary 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 should include:

- printed and digital information
- face-to-face meetings
- phone calls
- telephone helpline, 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 clearly involved, so long as the patient provides consent. When the patient refuses consent to provide information with the carer, this choice must be recorded with the patient to ensure the health professionals and support. Regardless of consent the carer will be supported to have their right and has the right to receive general information as well as being offered information to support and for a carer 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 when the patient is discharged.
- Encourage the carer to consider supporting an emergency plan in case anything happens to the carer which means they are unable to care. This will usually be arranged 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 the support plan for the carer if they have had a carer's assessment or access to their carer assessment during the period of hospitalisation, which outlines the support required and how this will be provided. Make this available as a home care planning for carers.
- The carer and the person they care for and support plan for the patient and the support plan for the carer should be in place. This should include any care contingency plan. It is important that a care contingency plan is completed with the carer's GP practice using ENHANCED CT Care under ENHANCED CT Care. This should be done as this will allow first responders to activate the plan during for continuity of care to be used for person.

Step Five Transition



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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 and hospital at home (April 2022) guidance

Hospital Carers Checklist Tool

Step 1

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

- Yes
- No

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

- Yes
- No

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

If no have you made a referral to social care?

- 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

Anything else

Hospital Carers Checklist Tool

Step 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

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

Hospital Carers Checklist

Helping to elevate the status young carers in NHS settings

Working alongside the Young Carers Alliance -The toolkit makes 120 references to Young Carers and includes links to a range of best practice examples operating in trusts nationally



Support and benefits for carers also the Carers UK – ‘**Looking after someone**’ guide and

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).

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>



But what about Mental Health?

- Key points of law set down in the Health and Care Act apply equally to Mental Health Trust. According to the DH website *“Discharges from mental health hospitals are not within the scope of this guidance. However mental health trusts are encouraged to embed some of the principles, adapted for mental health care pathways. Separate guidance will be published for those being discharged from mental health settings in due course.”*
- This promised guidance for Mental Health would also be issued under the Health and Care Act (as with the main Guidance). The same duties to cooperate also apply with regard to the Care Act 2014, Children Act 1989 and Health and Care Act 2006.
.....And why would we treat Mental Health carers differently to any other carers. This would be discriminatory!
- [Mental Health Act 1983 Code of practice](#) (243 references to carers) last updated 2017
- NICE Guidance 108 - [NICE guideline on decision-making and mental capacity](#).
- NICE Guidance 53 – [Transition between inpatient mental health settings and community or care home settings](#)
- NICE Guidance 150 – [Adult Carers Support](#)
- Triangle of Care 6 standards – Best practice



Carers and Hospital Discharge toolkit

Weblinks:

- <https://www.england.nhs.uk/london/our-work/carers-and-hospital-discharge/>
- [Carers and Hospital Discharge Toolkit for London Hospitals and Community Providers - Resources - Carers Trust](#)
- <https://carers.org/news-and-media/news/post/251-how-a-new-toolkit-will-improve-the-hospital-discharge-experience-for-patients-and-their-family-carers>
- <https://www.carersfirst.org.uk/news-and-stories/launch-of-new-hospital-discharge-toolkit-for-carers/>
- <https://enfieldcarers.org/carers-and-hospital-discharge-toolkit/>
- <https://www.carers-network.org.uk/help-and-advice/news-and-updates/post/67-carers-and-hospital-discharge-toolkit>
- <https://organisations.mobiliseonline.co.uk/mobilise-nhs-hospital-discharge-toolkit>



YOUNG CARERS

A gentle reminder

Being a young carer is not a child's real identity. It's a professional label we give them.

We need to be very careful to ensure that by lionizing young carers we don't forget our primary duty to protect children from inappropriate levels of caring.

There are no prizes waiting at adulthood for young carers who simply endure. The opposite, in fact, is true.

THANK YOU

Ros Spinks

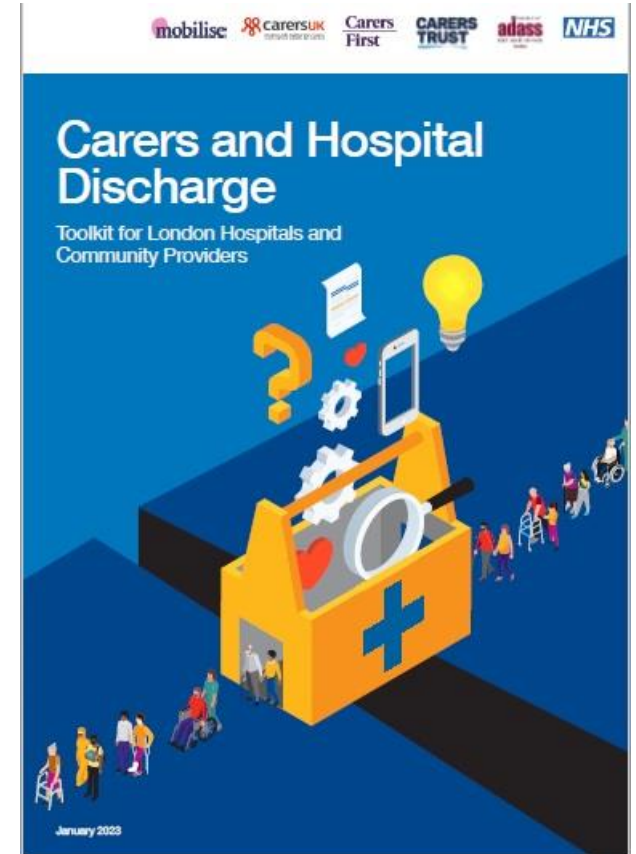


ros.spinks@nhs.net



@CarersLDN

[London Carers and Hospital Discharge Toolkit](#)



Young Carers' Support Service

Laura Greene
Kingston Hospital NHS
Foundation Trust



HOW CAN YOU TELL IF YOU ARE A YOUNG CARER?

Does someone in your family have a learning disability, physical disability, mental health condition, substance misuse or long term illness?

We are here to listen to you and offer our help where we can

You may be a **YOUNG CARER**

Speak to a member of hospital staff today

NHS
Kingston Hospital
NHS Foundation Trust

In partnership with

Richmond Carers Centre

KCN KINGSTON CARERS' NETWORK
Improving the lives of carers in Kingston
CARERS TRUST

Questions

1. How can we further promote the service so that young carers' think 'that sounds like me...'
2. How can we work with the education sector to ensure that schools are prioritising young carers' health and life opportunities
3. How can we lobby for greater guidance, e.g. NICE Guideline on how to support young carers in a healthcare setting – no wrong door principle
4. Kingston Hospital is a safe haven – how can we improve services for young carers thinking of us as a 1 Stop Shop for Young Carers accessing advice and support



Care for me too!

London Young Carers Data

Royal Borough of Kingston as a case study

The Census 2021 data evidenced that there were 340 young carers (5-17 years old) in the Royal Borough of Kingston. For this census they did not ask people aged under 5 years whether they provided care.

Kingston Carers Network are currently supporting 925 young carers!

Research by Professor Saul Becker and Nottingham University suggest that there is 1:12 young carers per classroom. This places the number of young carers in London closer to 150,000 which is more than the national census identified 127,000

If a child starts school with a health inequality as things stand we will never close it.....



Tweet



Oritsé Williams

@Oritse

One of my biggest frustrations in life, is no matter how hard I fight for it, or how much I try to campaign for change, young carers just seem to constantly be forgotten about 💔 in so many areas where they deserve to have a platform for their voices to be heard.

[#YoungCarers](#) 🙏

19:08 · 06/05/2023 from Earth · **7,031** Views



Legislation and Policy

Health and Care Act 2022

The legislation makes clear that, as the NHS is an all-age service, the term carer includes young carers. It introduced 3 clear additional rights/duties in relation to young carers:

- The right to be involved in discharge planning conversations
- A duty on Integrated Care Boards to consult with young carers around services provided to the adult they care for
- A duty on Integrated Care Boards for young carers to be consulted around planning and commissioning of services
- A duty on Integrated Care Boards to promote the involvement of each carer, where appropriate, in relation to decisions about diagnosis, treatment and care

The Health and Care Act 2022 - Section 91

- Places a 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.
- The new statutory 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 highlights the need to “ensure that no carers are left without adequate support or an assessment of their longer-term needs (if needed).”

Enhanced NHS Responsibilities

The Health and Care Act enhances the rights achieved for carers and young carers under the **Care Act 2014** and **Children and Families Act 2014**:

- Duty on NHS to co-operate with Council (Care Act re-emphasised)
- Duty to integrate (links to Better Care Fund)
- Prevention – includes promotion of physical and mental health and wellbeing for carers
- Provide information and advice and identify carers and young carers
- The current boundary between local authority responsibilities and NHS Continuing care*. These were defined in the Pamela Coughlan Court of Appeal judgment which set the threshold for NHS CHC.
- Use a whole-family approach to ensure young carers are not undertaking inappropriate or excessive care, and can make successful transition to adult life

*[National framework for NHS continuing healthcare and NHS-funded nursing care 2019](#) updated May 2022

[Care and Support Statutory Guidance](#) updated 2nd Sept 2022 (Revoked scheduled 3 and amended section 74 of Care Act 2014)

[Virtual Ward Guidance](#) published April 2022

Kingston Hospital's Young Carers' Service



HOW CAN YOU TELL IF YOU ARE A YOUNG CARER?

Does someone in your family have a learning disability, physical disability, mental health condition, substance misuse or long term illness?

We are here to listen to you and offer our help where we can

You may be a **YOUNG CARER**

Speak to a member of hospital staff today



NHS
Kingston Hospital
NHS Foundation Trust

In partnership with

KCN KINGSTON CARERS' NETWORK
Improving the lives of Carers in Kingston

Richmond Carers Centre

Detailed service provision

Parent Carers' Wellbeing Checklist & Consent to Engage with YP

Parent Carers' Advice Letter

Collaborative working with the Safeguarding Team

Young Carers' Wellbeing Checklist

Young Carers' Advice Letter

Young Carers' Safe Transitions of Care – what happens next

Clinical Liaison – advocacy and representation of young carers' voices

Employer / School / GP liaison

The Young Carers' Service launched in June 2023

- 12 referrals to date
- Presentation of complex case
 1. How can we further promote the service so that young carers' think 'that sounds like me...'
 2. How can we work with the education sector to ensure that schools are prioritising young carers' health and life opportunities
 3. How can we lobby for greater guidance, e.g. NICE Guideline on how to support young carers in a healthcare setting – no wrong door principle
 4. Kingston Hospital is a safe haven – how can we improve services for young carers thinking of us as a "1 Stop Shop" for Young Carers accessing advice and support





Q&A



@YCAAlliance

@CarersTrust



10 minute comfort break



@YCAAlliance

@CarersTrust



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Young Carers in Healthcare Project

Family Action Young Carers

Kate Anderson, Senior Practitioner

kate.anderson@family-action.org.uk

Tuesday 28th November 2023



Refer for a Young Carers Assessment



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Young Carers Assessment

RBWM Family Action is committed to making sure that caring is a positive experience for all young carers.

We provide a **4 – 6 month intervention**. Families are able to re-refer to our service at any point as long as there continues to be a support need for a caring role within the family.

Support Offer includes;

- Referrals and signposting
- One to one support
- Family sessions
- Targeted group work
- Representation at meetings
- YC Ambassadors Programme



A 6- Stage Wellbeing Programme for Young Carers





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Our responsibility and our role

As a society we have a **collective responsibility** to identify gaps in service provision and find ways across professions to meet these needs

To **raise awareness** of professionals about the long-term impact of caring on YCs mental health, future attainment, loneliness and vulnerability



Young Carers Legal Rights

- **Children and Families Act, 2014**
- **Care Act, 2014**

Local Authorities (LAs) must

- Identify Young Carers in their area.
- Assess and identify the support needs of Young Carers.
- Assess Young Carers at transition to Adult Services. (Care Act, (2014)
- NHS bodies have statutory obligations to cooperate with councils
- **Health and Care Act 2022 (and Mental Health Bill)**
 - Young Carers to be consulted with during discussions about planning for discharge and long-term care plans.
- **Equality Act 2010**
 - Young Carers are protected against discrimination and harassment

My Reflective Questions:

Q. To what extent is this happening in reality?

Q. How effective is this legislation?

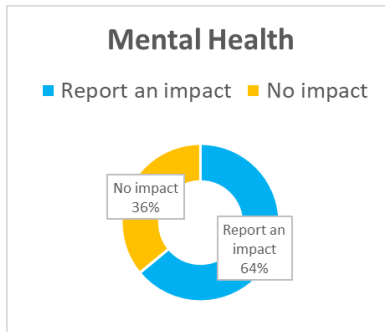
Q. Where is the accountability for ensuring this legislation is being followed in the spirit it was originally intended for the benefit of Young Carers?



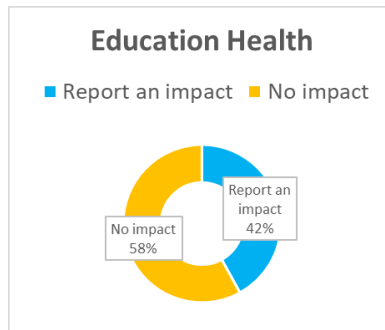
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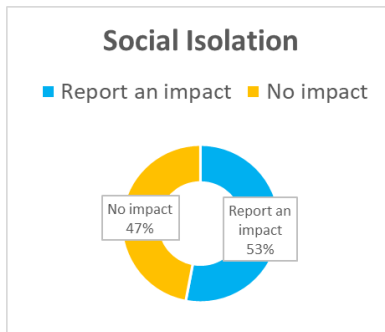
Impact of Caring – YCs in RBWM 2022/23



64% of Young Carers in RBWM reported that **their caring role impacted their own mental health**, of which 20% were accessing formal support.



42% of Young Carers reported an **impact on their education**. Since June 2020, 25% of schools in RBWM have trained Young Carer Champions, working in partnership with Family Action to support Young Carers in situ.



53% of Young Carers reported **feeling socially isolated**, increasing year on year as we have emerged out of COVID restrictions. During the pandemic (2020/21) this figure dropped to 35%.





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**How many referrals do you think
were made to RBWM FAYC from the
Healthcare Sector in the 5 years
preceding 2022?**





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How many referrals do you think were made to FAYC from the Healthcare Sector in the 5 years preceding 2022?

9

FAYC RBWM work with approximately 100 Young Carers per annum, the majority of referrals received from education and social care sectors.



Young Carers in Healthcare Roundtable Workshop



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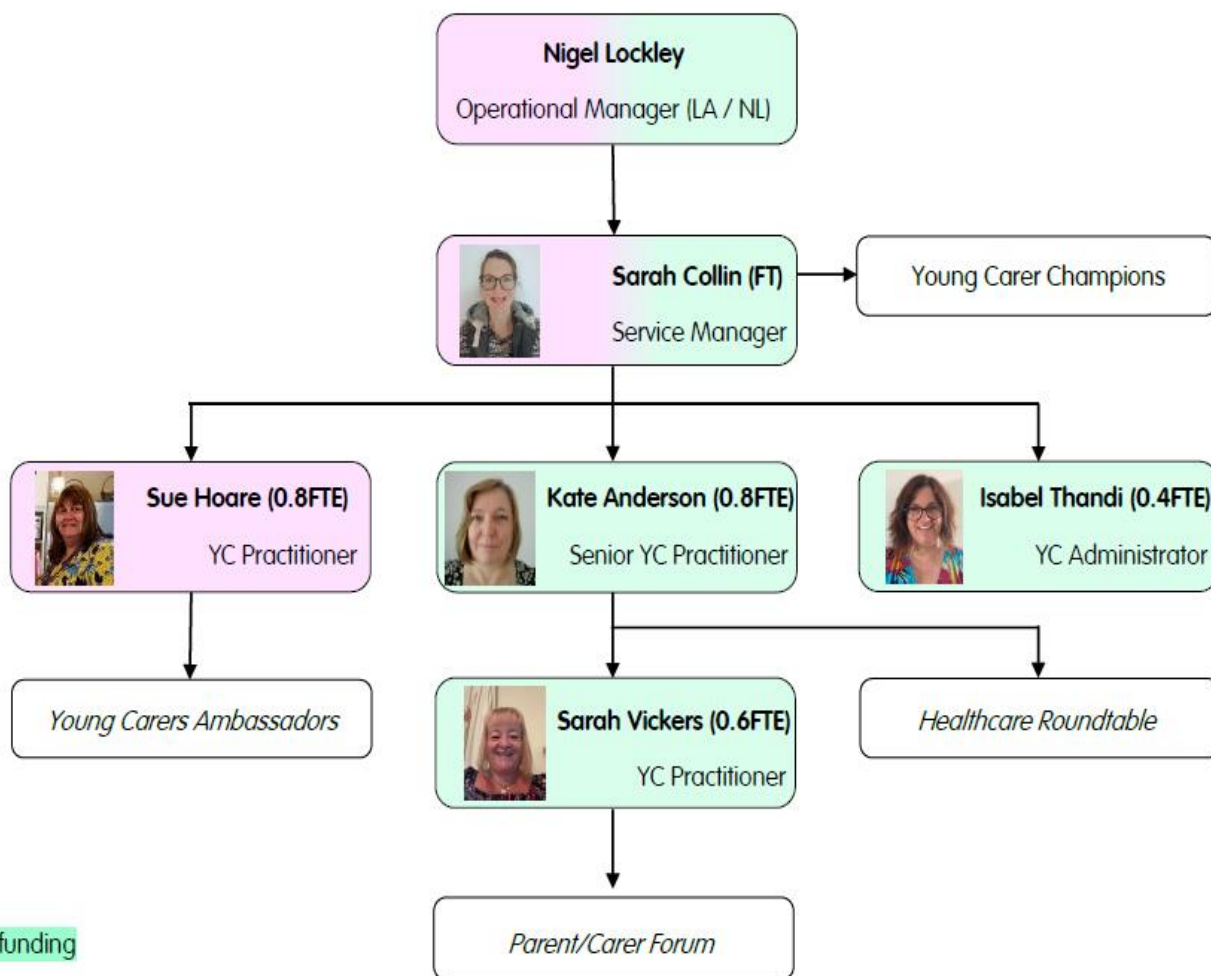
Originally, initial discussions were facilitated with key professionals with an interest in raising awareness of Young Carers by way of the Young Carers in Healthcare Roundtable Workshop.



One of the outcomes of these discussions was the move to apply to The National Lottery for Funding for a Young Carers in Healthcare Project to tackle the low rate of referrals from the Healthcare Sector and the Healthcare Project was born in April 2022.



RBWM Young Carers Staff Structure



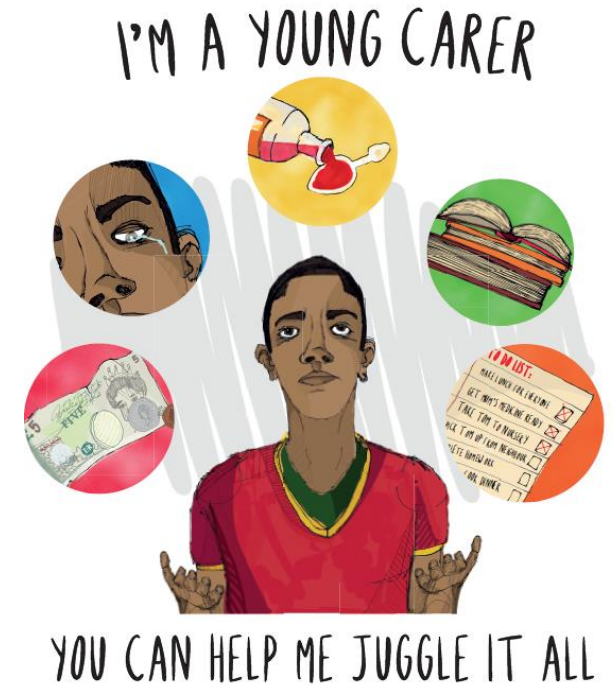
National Lottery funding

Local Authority funding



Aims of the project

1. **Professionals training:** Raise awareness of Young Carers in the healthcare sector and create suitable referral pathways
2. **Young Carer Assessments:** Empower families to Identify support needs
3. **Direct support:** reduce inappropriate or excessive care, and improve outcomes for young carers



Roundtable Discussions highlighted the fact Young Carers remain hidden – Main professional barriers identified:



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SKIVING?
NO. CARING

- Healthcare approaches to assessments and asking key questions, i.e. Is there a child in the family? – Encouragement to “Think family!” Who will provide day to day caring support?
- Capacity of healthcare professionals to include consideration of Young Carers, attend training, etc. Training has been adapted in timescales and times and modes, i.e. short, 45 min. on-line courses offered, ½ day, face to face, etc.
- Unsuitable referral routes.
- Incompatible systems for recording and sharing information between professionals, difficulties in gathering comparable data, etc.





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Referral Pathway and Induction Training.

- RBWM FAYC achieved a review of referral pathway which was considered to be streamlined, containing key relevant information. “No wrong door”...as long as the referral reaches us.
- Including training at induction in all healthcare departments would raise awareness with all healthcare professionals and capture their attention as they come into post to embed awareness of YC’s at induction. Hard work has been done to explore this opportunity as an effective solution to raise awareness among healthcare professionals, but the implementation of this appears to have been blocked at senior management levels.



Reviewing Healthcare Department Assessments and Frontline practice.



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- Encouraging reviews of healthcare assessment forms and practice has been identified as a possible solution to support awareness of frontline healthcare professionals when they are assessing their patients.
- Encouraging professionals to “think family” in their assessments and ask key questions to identify children in the household who may be impacted by a caring role and offer support continues at TTT, Young Carers Champions, sessions and at the Young Carers in Healthcare Roundtable Workshop



The London Carers' Discharge Toolkit - my reflection.



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- The London Carers Discharge Toolkit, launched in January 2023 in London hospitals, has been created as a wonderful example of where this issue of assessment and frontline practice has been addressed by senior management across many NHS departments and voluntary sector partners within hospital settings.
- For my part, it has taken over a year to be able to access a hospital discharge team meeting, being signposted to so many different professionals. Communication, healthcare professionals' time, and availability to organise team meetings have played a role.
 - Aware that frontline workers were not aware of this toolkit
 - What is a Young Carer?
- London Carers Discharge Toolkit – 6 months on, the degree of take-up of this guidance varies considerably. The positive practice message did not appear to have reached as many frontline healthcare professionals as hoped, many in our area's main hospital appearing to be unaware of the toolkit and may not have been afforded the opportunity to read through it as a team.



Communication and Training.



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- FAYC, RBWM, have created and adapted training for Healthcare professionals reducing it to 45 minute “bite-size” sessions as part of the free training we offer, but still few healthcare professionals are able to take up this offer.
- Many frontline healthcare workers are keen to attend the training, including the Champions Train the Trainer Training, but on the day, they are usually unable to attend, possibly due to the demands on their time in their daily role.
- Incompatible processes and systems for recording and sharing information between professionals, difficulties in gathering comparable data, etc. remain a significant issue between departments. When young carers have been identified, we have been sending letter requests to GP’s to activate their young carer SNOMED codes on their database system over the last year, but evidence has shown not all GP surgeries are actioning this request and only 5 GP surgeries in the borough demonstrating that they are pro-actively using the SNOMED codes as requested.





Means of Communication with Families and Professionals.



Young Carers in Healthcare Project

Family Action is a charity committed to identifying and proactive in the RBWM since 2016. Implementing a holist with Young Carers, their families, the wider community the negative impact their caring role may induce. Som support, access to local services, liaising with schools fun days out! We believe it is important to instill You as happy and healthy young people.

We have built a strong foundation within the lo Carers each year. At present we also have organisations and school settings, advocating so, Young Carers are still being missed, data Carers across the RBWM, and so more wor

We believe the healthcare sector is ide understand the struggles Young Carers fo of contact for many families when expe conditions or substance misuse issu families and initiate the opening up professional agencies for families. T have a holistic support network are

In April 2022, funded by the Nati Carers in Healthcare Project, a professionals and Family Action members of staff, a Senior Administrator. And so, as pa clear referral pathway for h and intervention for Young

As such, to ensure we appreciate your supp networks to raise awc care planning stages

For further informati Isabel.Thandi@fa

Newsletter

Autumn 2023

rbwm.yc@family-action.org.uk

Welcomes



We are delighted to welcome Isabel Thandi, who is joining our Young Carers Team Administrator! She brings a wealth of ex children and families as well as excellent organisational skills to smoothly as possible.

The voice of Parents/Carers

Thurs 28th September 12pm - 1pm - Parent/Carer Forum Meeting (MS Teams)
The role of a forum member is to be a voice for young carers and their families, to express experiences in regards the identification and support of young carers within healthcare, ed community, and local authority services. It allows parents/carers the opportunity to work with Action to make a difference to young carer support within RBWM.
Email rbwm.yc@family-action.org.uk to sign up to attend

Thurs 23rd November 4pm - 5pm - Very Young Carers Consultation (Maidenhead Project Cen)
We are aiming to develop our support for school years Reception - Year 2 and would value parent/carers views on what a good offer of support looks like. Bring your Very Young Carer along with you for an engaging craft session and share your thoughts with our team.
Email rbwm.yc@family-action.org.uk to sign up to attend

Young Carer Ambassadors

Our Young Carers Ambassadors programme has got off to a flying start. In early September, 4 new Young Carers trained to take on this exciting role to work with our team, be a role model to other young carers and share their personal experiences on a local and National level to shape the support on offer to Young Ambassadors will meet on a monthly basis, and be taken through a programme of leadership development, social action and celebration.



Family Action Young Carers 2023/24 Professionals Training Schedule

Family Action Young Carers are delivering a series of information and training academic year. These sessions are open to all professionals regardless of wh young people or adults.

All training is free to attend. Please see full details below of the sessions or For further enquiries, please contact our team at rbwm.yc@family-action

Please visit our [website](https://www.family-action.org.uk) for further information about our service and

An Introduction to Young Carers (1 hour virtual)

This webinar is designed to raise awareness of young carers young carers may face and support practitioners to be mor carers in their own area of practice regardless of whether adults.

- 19th September 2023, 3.30 - 4.30pm | [Register here](#)
- 9th January 2024, 3.30 - 4.30pm | [Register here](#)
- 30th April 2024, 3.30 - 4.30pm | [Register here](#)

Train the Trainer (4 hours)

We recommend that services nominate to attend this training.

- Training objectives:
- To understand the roles of
 - To understand the legal
 - To engage with Young
 - To explore how to en

On completion of this co within their workplace attend our termly Refly

- 14th November 20
- 23rd April 2024,
- 24th April 2024,



family action



Young Carers and the School Census (45 minute virtual)

In Spring 2023, young carers were included on the school census return. This session is to assist schools to prepare to identify young carers and explore how to support young carers within their school environment.

Training objectives:

- To develop insight of the roles and responsibilities of a young carer and when they may need additional support from Young Carers Services
- To establish an environment for Young Carers to be identified, coded and supported within your school
- Gain a greater understanding of specialist Young Carer support

Family Action will be delivering this session a few weeks prior to each census data collection:

- 19th September 2023, 9.15 - 10am | [Register here](#)
- 9th January 2024, 9.15 - 10am | [Register here](#)
- 30th April 2024, 9.15 - 10am | [Register here](#)

Young Carers and the NHS Long Term Plan (45 minute virtual)

It's often said that all of us are patients at some time in our lives, but it's less often acknowledged that most of us will also be unpaid carers too. Written in partnership with NHS England, this training is for all healthcare workers, whether your work is with children, young people or adults, to assist with identifying Young Carers within the workplace setting and explore how Young Carers can be best supported.

Training objectives:

- To develop insight of the roles and responsibilities of a young carer and when they may need additional support from Young Carers Services
- To establish routine enquiry approaches for Young Carers to be identified, coded and supported
- Gain a greater understanding of specialist Young Carer support

Family Action will be delivering this session a few weeks prior to each census data collection:

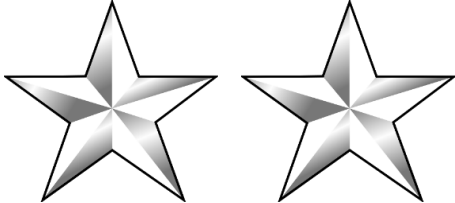
- 19th October 2023, 9.15 - 10am | [Register here](#)
- 19th October 2023, 12.30 - 1.15pm | [Register here](#)
- 22nd February 2024, 9.15 - 10am | [Register here](#)
- 22nd February 2024, 12.30 - 1.15pm | [Register here](#)
- 16th May 2024, 9.15 - 10am | [Register here](#)
- 16th May 2024, 12.30 - 1.15pm | [Register here](#)

Young Carers Award Scheme

Young Carer Ambassadors



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Young Carers Award Standards for Healthcare settings



Building stronger families

	Phase One: Sign Up and vision	Complete	Evidence
SILVER AWARD	1. Acknowledge and understand the importance of supporting young carers (reflected in principle healthcare documents)		Attach document for review
	2. Develop a Young Carers' Policy, and amend other relevant policies to reflect the specific needs of young carers and their families		Attach document for review
	Phase Two: Young Carer Champion	Complete	Evidence
	1. Assign a member/s of staff as Young Carer Champion to ensure young carers have a trusted adult they can turn to		Name of Champion/s:
	2. Young Carer Champion/s to attend Train the Trainer on the Identification and Support of Young Carers in your Workplace, delivered by Family Action Young Carers		Date attended:
	3. Ensure Young Carer Champion/s has a route to escalate issues to senior management		Escalation route:
	4. Ensure staff know how to refer to local young carers' support for specialist young carer support		
	Phase Three: Raising awareness	Complete	Evidence
	1. Young Carer Champion to deliver awareness training to all staff, as part of all staff professional development		Training type/date:
	2. Embed Young Carers' awareness into wider patient care		Practice example:
Phase Four: Identification and monitoring of young carers	Complete	Evidence	
GOLD AWARD	1. Ensure there is a Young Carer flag on your system and that it is being used (e.g. EMIS code: Child Carer)		Practice example:
	2. Review process to identify parent/s, siblings or family members who have physical or learning disabilities, long-term physical or mental illness or misuses substances		Practice example:
	3. Make information about your workplace and local young carers support available (e.g. noticeboard, website, intranet, newsletters)		Practice example:
	Phase Five: Ongoing support for young carers and their families	Complete	Evidence
	1. Ensure that your workplace, events and all communications are accessible to ensure patients can fully support their children in their role as young carers		Practice example:
	2. Develop practical support (e.g. health clinics, double appointments, drop in sessions)		Practice example:

For more information on how Family Action Young Carers can support you in identifying and supporting young carers, please contact rbwm.yc@family-action.org.uk



Reasons to be cheerful and thankful



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- We have reached 17 healthcare referrals by Q2 of the Year 2 of the Healthcare Project, on track to reach our target of 36 for this year.
- We have reviewed and streamlined our referral pathway.
- We have attended healthcare professionals' team meetings to raise awareness of young carers, including a hospital discharge team of 22 frontline practitioners, health visitors and school nurses and mental health practitioners.
- We had a Social Prescriber designated to supporting children and their families attending our Young Carers Champion event on 14th November, 2023 and healthcare professionals have opportunity to choose from a schedule of accessible Training Events run by FAYC RBWM.
- Young Carers Roundtable Workshop Event continues via Eventbrite, on-line, continuing the conversation with the healthcare sector, giving healthcare professionals opportunity to have their say in how RBWM FAYC can develop our service and support healthcare professionals to raise awareness of Young Carers and increase the rate of referrals.
- We have successfully raised awareness of Young Carers with some G.P.'s through our letters requesting activation of their SNOMED Codes on their database system, although more work is to be done in this area.



Challenges for the future:



- Maintaining/increasing funding and capacity to fulfil our role more effectively.
- Developing our service to meet the needs of very young carers aged 5 to 7. We recently held a very young carers' event alongside our parent carer forum to explore what parents would find helpful as a service. We currently do not offer a service to under 5's, although their needs have been recognised by Health Visitors.
- Developing our service to meet the needs of young adult carers at transition and beyond.
- Continuing to raise awareness amongst healthcare professionals, especially in adult services, to think family and adopt a more holistic approach to assessment and legislation and guidance. Developing a strategy at senior management level to challenge the mindset of policy and decision-makers to include raising awareness of Young Carers at induction into the healthcare profession.
- Keep up to date with current research, in particular any outcomes of longitudinal studies which will help provide an evidence-base for our progressing the NHS long-term plan.
- To encourage communication between professionals in the same setting, e.g. facilitating Census information to be shared with Young Carers Champions and School Nurses, between internal hospital departments, etc.



Final Reflections



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At Family Action Young Carers in RBWM, we share the view that:

If we are to build an NHS that is fit for the future then carers must be **full partners** in the way care is delivered.

We must join up our services around carers' needs as well as those of the patient and we must **help them look after their health and wellbeing** to enable them to sustain their vital caring role.





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For enquiries

rbwm.yc@family-action.org.uk

To make a referral

rbwm.referrals@family-action.org.uk



Practice Example – Caring Together

Belinda Jones

Carer Awareness and
Voice Team Manager



@YCAAlliance

@CarersTrust



Hosted by

**CARERS
TRUST**

Young Carers and Health



About us

At Caring Together our vision is a world with no unpaid carer in crisis, isolated or struggling alone.

We are passionate about helping people get the practical support and advice that really makes a difference to them – before, during and after their caring role.



3 in 5

More than 3 in 5 of us will become an unpaid carer.



12,000

Every day, on average, 12,000 people in the UK take on a caring role. That's 82,000 people a week.





Norfolk Young Carers Forum



Carer Friendly Tick Award



Awareness engagement

🌸 Awareness raising activities

🌸 Carer Friendly Hospitals and Trusts

🌸 0-19 Healthy Child Programme

🌸 Directory of services –East of England Ambulance service

🌸 Integrated Care 24 - Norfolk & Waveney 111 service

🌸 Primary Care – Top Tips for GP's – NHS England

Top Tips for GP's

Young Carer Voice

Young Carers speaking about Top Tips for GP's
<https://www.youtube.com/watch?v=Ld7RXvTNHOQ>



Primary Care – Top Tips

Five ways you can make a big difference to young carers. Here is how, in their words.



Think about the support and understanding a young carer may need.



Listen and hear what young carers are saying.



Recognise that young carers have individual needs and shouldn't all be treated the same.



Avoid relying on young carers interpreting for the person they care for.



Think about how you can make appointments more accessible; after school, double appointments, etc.

“
If a GP could recognise my individual needs and be able to help others understand those needs, it would lift some weight off my shoulders.
”

 **Caring Together**
so that carers have choices
caringtogether.org



#NHSThinkCarer



Carers Identity Passport

Digital and/or physical carers passports available.



I am a Carer

I look after someone who depends on me

Carer Name:

Carer Identity Passport Number:

Issue Date:



This card has been issued by Carers Voice Norfolk & Waveney on behalf of the Norfolk and Waveney Integrated Care System

To find out more information on the support available for Carers, visit improvinglivesnw.org.uk/carers or scan the QR code



If this card is found, please contact: info@carersvoice.org

Scan this QR code to find out more and apply for your Carers Identity Passport.

Reach for the skies

- Thorpe Woodlands Adventure Centre
- Young Carers and YC services co-produced
- Swap caring for activities and a night's glamping
- Information 'Market Place' with career and healthcare advice
- Inspirational speakers
- Musical entertainment
- Festival feeling



James' Story

Norfolk and Norwich University Hospital



Any Questions?

Cambridgeshire

L D H House, Parsons Green
St Ives
Cambridgeshire
PE27 4AA
T: 0345 241 0954
E: hello@caringtogether.org
www.caringtogether.org

Norfolk

37A Turbine Way
Swaffham
Norfolk
PE37 7XD
T: 0345 241 0954
E: hello@caringtogether.org
www.caringtogether.org



Practice example – Centre 33

Charlotte Doyle
Senior Young Carers Project Worker –
Capacity Building

@YCAAlliance

@CarersTrust





Q&A/Discussion



@YCAAlliance

@CarersTrust

Thank you



To find out more about the Young Carers Alliance or become a member/subscribe to updates



www.youngcarersalliance.org



youngcarersalliance@carers.org



[@YCAAlliance](https://twitter.com/YCAAlliance)

Please do provide feedback on today's event - [Young Carers Alliance Event Feedback Form](#)