South Tees Carers Forum

Recognising and identifying Carers

A Strategy for all Carers

There is no such thing as a 'typical Carer'. The <u>South Tees Carers Strategy 2021-26</u> and <u>Action Plan</u> that accompanies it, seek to identify, recognise, engage and support all unpaid/informal Carers of all ages and backgrounds to ensure their needs are understood and met. This requires a better understanding and awareness of Carers' needs, their diversity and the diversity of the people they care for, as well as the complexity of their caring roles and responsibilities and the impact these have on their lives.

Some Carers are registered or known to statutory organisations and others providing health and social care services and may access services and support. Some are 'hidden Carers' who, for various reasons, do not identify as Carers and/or do not engage with services or receive support. Many enjoy and value their caring role, some may struggle.

There are an estimated 14,000 Carers in Middlesbrough and 16,000 in Redcar & Cleveland, although the Strategy and Action Plan recognise that these figures are likely to be inaccurate and there is a lack of robust data. A series of objectives, outcomes and actions have been collectively agreed to rectify this and provide better intelligence on the numbers and types of Carers, as well as their needs, engagement with and the impact of services and support¹.

The Strategy recognises the need to raise awareness of the needs, challenges and issues of all Carers, whoever they are, wherever they are in South Tees and to understand their challenges, needs and aspirations. It seeks to ensure their views are heard and that they are represented and can influence the services and support that should be available to them. There is also a need to make sure that all policies, plans and strategies across all services in South Tees reflect these needs and promote integrated working and services which support Carers, underpinned by robust data and evidence and a coherent and clear communications and engagement plan.

Who are the Carers?

Definitions:

A Carer is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid.'²

A Carer is anyone who provides unpaid care and support for another person³

The list of definitions of Carers provided overleaf aims to raise awareness of the types of Carers and the cared for, but it is not an exhaustive list and it should be noted that:

- some Carers will fall into more than one category or definition and may also provide care for more than one person and those cared for may have different care needs
- some will identify as Carers and be officially recognised, but may or may not receive or want support
- some identified Carers may access some services (such as health and social care), but not other services (such as education, training, employment, housing, financial, business support and others)
- some will be 'hidden Carers' and may not receive any recognition, services or support for their caring roles and responsibilities and some of these Carers may not need or want support

¹ South Tees Carers Strategy 2021-26 and Action Plan 2021-22 and South Tees Carers Forum on We Care You Care website

² NHS England reference to the definition of carers

³ Definition recommended by South Tees Carers Forum to raise awareness of Carers in the most simple and direct way

Young Carers	Children and young people up to 18 years old providing care for a relative. Young Carers are not on the Census and there is no central collection of data about them. Although some are identified and receive support, many are 'hidden'. Adults and family members may not wish to identify the young person as a Carer for a whole host of reasons (including drug and alcohol issues, feeling that if authorities think they cannot cope their child/ren will be taken away). Young people may not identify themselves as a Carer and may not be aware of support available. Schools and others who come into contact with Young Carers may not identify them as such or be aware of their support needs.
Young Adult Carers	Young people 18-25 who have transitioned from being children to adults and have maintained their caring roles and responsibilities. These young people can be lost between Children's Services and Adult Social Care services, if they are registered or known about. The NHS, national carers policy and Carers support services recommend support from 16+ to support the transition from Young Carer to Young Adult Carer.
Adult Carers	Any Carer over 18 years old
Parent Carers	Parents of children with care needs, who may be caring for children (both under 18, but also adults) who may have a range of comorbidities alongside a condition that they have been (or may not have been officially) diagnosed with. These may be physical disabilities, learning disabilities, neurological conditions or other health problems. They are often overlooked in strategies relating to Carers. They may be reluctant to identify themselves or challenging services, for fear of repercussions against them and the perceived threat of the cared for person being removed from their care.
Kinship Carers	Carers who are parents, grandparents, friends and family members, who have caring responsibilities for family members or friends.
Foster or Adoption Carers	People who are or were Carers in the fostering and adoption system, who may not be recognised as unpaid Carers, depending on where they are in the fostering and adoption journey.
Very Elderly Carers	These Carers have caring responsibilities for their spouses or others in their family and are in their 70s, 80s and 90s, so may be struggling themselves with memory loss, mental health issues and loneliness, as well as physical frailty.
Working Carers	People who are in full time, part time paid employment or who are self employed or run a business, but also provide unpaid care for family or friends with care needs.
Carers from BAME communities	Carers from different Black and Minority Ethnic communities, with different languages and cultural backgrounds. They may not come into contact with statutory services or recognise themselves as Carers, as they may see their caring roles as part of their normal family responsibilities and as part of their culture of caring.
Refugees/Asylum Seeker Carers	These Carers may not be registered with Social Care due to their immigration status, but may receive some services and support through other providers.
Carers who are economic migrants	These include people who have come to the UK to find work and may come from a wide range of countries and have a diverse range of cultural and social backgrounds, as well as differing attitudes and trust of authorities.
Carers who are learning or physically disabled or health issues	These Carers may have learning disabilities, physical disabilities or other health issues. They may be reluctant to be identified or to access services if they are concerned that the cared for person would be removed from their care if they were deemed to be unable to cope with the caring responsibilities.

There are also Carers who can be recognised by the type of issue or caring need that the cared for person has. These may also fall into one or more of the previous categories of Carers as well.

Carers of people with neurological conditions	Carers of children or adults (including adult children) with neuro developmental conditions can struggle to get support or a care pathway. Some conditions are rare, not well known, misdiagnosed or undiagnosed. Some people are referred to mental health, where there should be a primary diagnosis with mental health co-morbidities. Autism Spectrum Disorders are more well known, but not always diagnosed. Foetal Alcohol Spectrum Disorder is not openly recognised or diagnosed and often missed as a primary diagnosis, locking people out from support. This is also the case with rare conditions such as Friedreich's Ataxia, which is a debilitating life limiting condition and also Acquired Brain Injury. There are also conditions such as Narcissistic Personality Disorder, which can result in abusive relationships, but may not be recognised by support services and the Carer may feel unable or unwilling to access support.
Carers of people with dementia	Carers for family members or friends with different types of dementia and at different stages or degrees of advancement and different ages, may or may not come into contact with local authorities and voluntary sector organisations, projects or initiatives.
Carers of people who lack mental capacity	Some will be identified through the Lasting Power of Attorney process where there are agreements in place, some may be identified by support services and through work with solicitors to identify and offer support. Others may come into contact with the Deprivation of Liberty Standards team in Local Authorities
Carers of people who abuse drugs, alcohol, or have addiction issues	These could be children, young people under 18, adult family members or friends who support people with addiction issues and may be 'hidden' as they or the cared for person do not want these issues to be known about

Ex-Carers transitioning from being a Carer to no longer having a caring role

Reasons for Carers becoming Ex-Carers and who no longer have a caring role might include bereavement of someone close or the death of the cared for person. Carers who have lost loved ones, such as partners, spouses or children who they have been with and cared for, for a long time, find it particularly difficult. The cared for person may have been taken into care, which is often traumatic, but exacerbated during the pandemic when they are unable to visit them in person. The Carer may feel unable or unwilling to continue in their caring for different reasons and may feel guilt. Whatever the circumstances, the impact of the transition to being an Ex-Carer can be traumatic and difficult and, in some cases, result in suicidal thoughts or suicide.

Why are Carers 'hidden'?

Carers may not identify themselves as such, for a variety of reasons, and would be classed as 'hidden'. In addition to some of the reasons listed with the definitions above, Carers may not identify themselves, as:

- it is part of what they do for their family and/or friends
- it is normal within their culture to care for family and friends and not seen as exceptional or something they would seek support for from statutory or other services
- they may be anxious of scrutiny from public authorities for a variety of reasons, unrelated to caring roles
- they may fear or have experience of a blame culture, where they have been made to feel that they are to blame for the situation of the cared for person or their own circumstances
- the socio-economic situation of families can mean that Carers from different backgrounds act and are treated differently (e.g. well-educated and well-off Parent Carers who could afford therapies and treatment for the cared for are also able to navigate the social care funds and system more confidently than those from poor backgrounds who can't) and professionals may treat them differently