East London Foundation Trust (ELFT) Carers and Families Strategy

(2021 – 2026)

CONTENT

FOREWORD

It is difficult to overstate the importance of the role that carers play in supporting people with physical health, mental health and learning disability needs. The work that they do to support their loved ones and to work closely with our teams is invaluable.

This strategy aims to ensure that the critical role of carers is acknowledged and respected - and that people's needs as carers are recognised and met.

The strategy has been designed and co-produced by carers and staff. We are committed to involving carers in our work, alongside the people who use our services and others with lived experience in our communities, including our staff.

Our organisation's strategic aims strive to involve people in driving and shaping services and to include them by promoting equality, valuing diversity and championing recovery. By doing this, we hope to continue to improve the quality of our services and people's experience of them.

Thank you to everyone who has shared their time to make this strategy a reality -

A CARERS VIEW

Have you heard the African proverb that says, 'it takes a village to raise a child'? It's one I have reflected on over the years and even more so now that I am a carer.

When my son was born our village was quite small with family and friends. As he grew older the village expanded to include his siblings, his friends, teachers, scout leaders, sports coaches and more. Now he is in early adulthood our village has unexpectedly grown to include a vital network of medical professionals, mental health workers, care workers, charities and of course, other carers like myself. But in the early days of my son's illness I had no idea I could find these people in 'our village' nor understand the vital help and support they could offer. To be honest, I had not considered myself a carer but simply a mum struggling to help my child.

Being a carer for someone you love can be very demanding: emotionally, physically and mentally with highs and lows that often requires resilience, strength and a good sense of humour! It's not a circumstance that most people would think they would find themselves in or a job description they would sign up to. Some care for their child, some for a friend or partner, others might be a child caring for their parent and most will be juggling other things in their lives such as work, family life or school and studying.

The ELFT Strategy recognises, respects and values the important role that carers play in both supporting a person using services and the staff who deliver these services and treatments because, working together as a team will help improve wellbeing for both carers and the cared for. As a carer who is still fairly new to the role, I know I will benefit from feeling supported and informed by staff committed to meeting my needs as well as those of my son.

INTRODUCTION

East London Foundation Trust Carers and Families Strategy is aligned to the broader ELFT mission pledge to 'improve the quality of life for all we serve' and shares our organisational vision that by 2022 we will 'lead on the delivery of integrated care'.

We will do this by 'working purposefully in collaboration with our communities and our partners, always striving towards continuous improvement in everything we do'.

The Strategy recognises the needs of carers of people using all our services, including community health services, mental health and learning disability services, primary care and child and adolescent mental health services (CAMHS) and recognises the unique needs of young carers.

We recognise that carers support enables many people to live independently and relieves pressure on hard pressed resources and services. Carers and service users are experts in their own care needs and should be seen as partners in the care pathway working alongside professionals to deliver best outcomes.

The Strategy sits alongside the strategies and plans produced by our local authority partners, and we aim to work in a complementary and joined up way with them and with the local voluntary sector partners and primary care.

This Strategy has been co-designed and co-produced with carers and staff and provides our services and directorates with **five key priority** areas which they address through detailed local delivery plans.

Individual plans describe how the key priorities will be addressed by the individual service areas, the tools and processes needed to create strong engagement between staff and carers, and the resources and learning needed by our staff to recognise and value carers as key partners and support them in their role.

The strategy describes what we want to do, how we are going to do it and what carers can expect. It identifies the ways in which we will measure our progress.

The five key priority areas for the Trust are:

1. **Improve identification and recognition of carers including young carers**

2. **Staff should be aware of carers and trained to engage with carers effectively**

3. **Clear pathways to access support for carers and help in a crisis**

4. **Carer voice and involvement**

5. **Ensure right support is in place for young carers**

WORKING TOGETHER

East London NHS Foundation Trust (ELFT) is committed to enabling people who use our services and their carers to have a say in how the Trust is run.
We know that by working together, we can make services better for all. This is where People Participation comes in.

People Participation connects service users and carers with opportunities to contribute to the development and improvement of ELFT services. We aim to support people to share their views and lived experience, and to help all of us learn new skills along the way.

https://www.elft.nhs.uk/get-involved/people-participation

WHO ARE CARERS?

You are considered a carer if you provide unpaid care to another person which can include practical help and/or emotional support. In the Care Act 2014, the description applies whether the carer or cared for live together or apart. You do not need to be eligible for carers allowance to be considered a carer.

Carers do not include someone who is paid to provide care or where care is provided by a carer organisation or a volunteer.

Carers come from all walks of life, all cultures and can be of any age. Many do not see themselves as carers, as for them the caring relationship is simply part of everyday normal life as a wife, husband, partner, son, daughter, sibling, parent or friend. However, being recognised as a carer can provide access to support, services, information and advice, which can help to make caring more manageable.

ELFT serves diverse communities, and many carers are from a Black, Asian and Minority Ethnic background. BAME carers face the same challenges as all carers, but also face additional barriers, for instance cultural barriers, stereotypes and language which can increase the chances of poorer health, poverty and social exclusion.

We are also committed to recognising the needs of carers as described by the ‘protected characteristics’ of the Equality Act: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, religion/belief, sex and sexual orientation as well as socio-economic status.

ELFT lead by example and provide a flexible working environment for carers in our workforce:

‘Making the Trust an excellent place to work is important to us and one of our key priorities. For this the Trust is doing a lot to improve the working lives of staff such as making flexible working hours available to those people who have younger children and/or who are carers. The Trust offers flexible working hours for staff with younger children or staff who are carers’

HOW DID WE DEVELOP THE STRATEGY?

This Strategy has been informed by engagement with carers, People Participation, carers leads and ELFT staff as captured in the table below:

Table 1

What’s been happening…	
Summer 2020	• Reflecting on the impact of Covid-19 and how services should adapt, the Trust identified the needs of carers as a priority
Autumn 2020	• A co-designed survey of carers about ‘health and life during the lockdown’ generated 91 detailed responses with the central message that ***the pandemic reinforced pre-existing problems and inequalities*** including: • The relationship between professionals and carers needs improving particularly information about services and communications between professionals, patients and carers. Getting this right would overcome any perception there is a lack of respect and recognition of the challenges faced by carers everyday • Changing service delivery – from face-to-face to virtual was a key theme emphasising ongoing access challenges and the need to support carers in times of change • The Trust must maintain an ongoing dialogue with carers to understand the diversity of experiences, drawing on the positive work of People Participation and voluntary and community sector support services
Winter 2020/21	• Senior leaders commit to refresh the Trust Carers Strategy

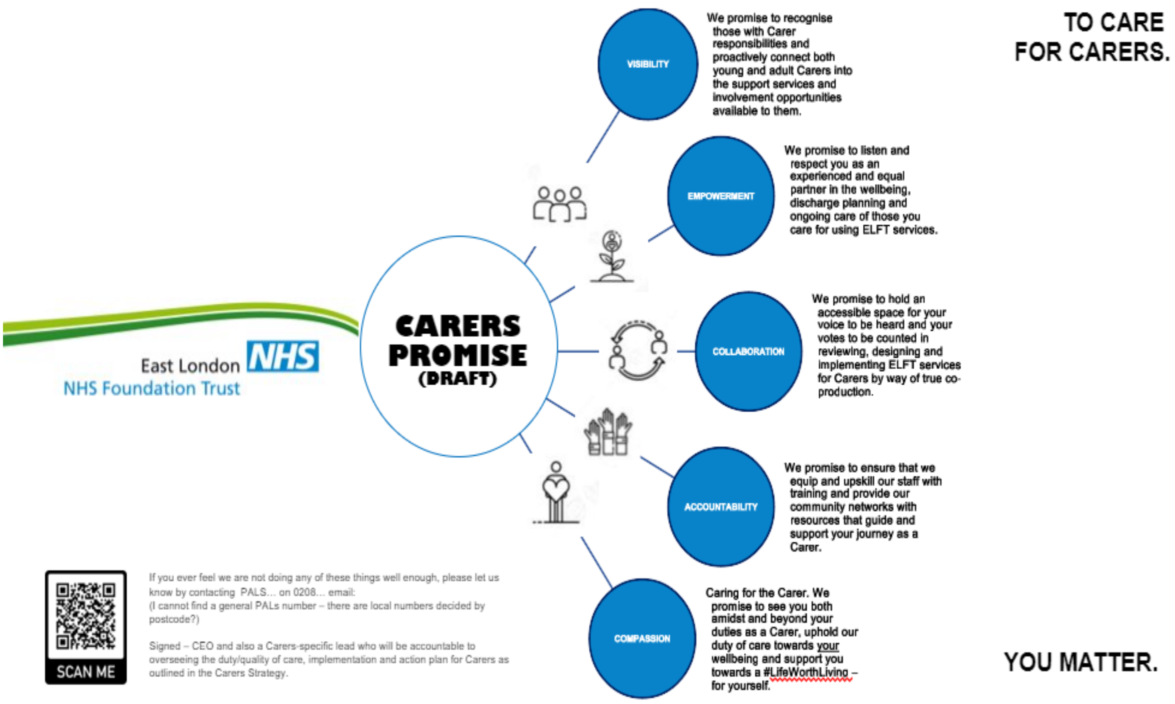
Spring 2021	• Using the NICE Quality Standards (https://www.nice.org.uk/guidance/qs200) a mapping exercise highlighted a range of existing services to support carers but variation across the Trust which needs to be more consistent
Summer 2021	• Focus groups with carers and those who work with them reinforced the messages from the survey and mapping with the following key headline: carers are a huge resource, so the Trust needs to strengthen its recognition of different needs and work more collaboratively. Open and honest communication, access to support and training were other areas highlighted. • In developing community mental health transformation work, the East London Working Together Group have made the following wishes: • To be truly seen, heard and understood as a carer • To improve the quality of care provided to my cared-for • To experience a better quality of life myself day-to-day and have a 'life worth living'
Autumn 2021	• Next steps to include further engagement about the revised Strategy and exploring how it can be delivered in different services and places

OUR PROMISE TO CARERS

We developed our Carers Promise set out below by listening to carers, talking with our staff and partners and reviewing best practice and policy. From that process we identified the key themes most important to carers and those which reflect best practice.

Our Promise to Carers signifies ambition and hope, it's a two-way interaction between us and carers. It encapsulates what we are about, our values, our behaviours. So when we talk about our strategy we talk a common language with service users, with our community and with our partners.

In addition to this we provide carers with a QR code which takes them to our strategy online. It will also provide them with helpful information and advice about the support available to them in their area and their local delivery plan. A different QR code for each area – but the same ELFT promise.



East London NHS
NHS Foundation Trust

CARERS PROMISE
(DRAFT)

TO CARE
FOR CARERS.

VISIBILITY We promise to recognise those with Carer responsibilities and proactively connect both young and adult Carers into the support services and involvement opportunities available to them.

EMPOWERMENT We promise to listen and respect you as an experienced and equal partner in the wellbeing, discharge planning and ongoing care of those you care for using ELFT services.

COLLABORATION We promise to hold an accessible space for your voice to be heard and your votes to be counted in reviewing, designing and implementing ELFT services for Carers by way of true co-production.

ACCOUNTABILITY We promise to ensure that we equip and upskill our staff with training and provide our community networks with resources that guide and support your journey as a Carer.

COMPASSION Caring for the Carer. We promise to see you both amidst and beyond your duties as a Carer, uphold our duty of care towards your wellbeing and support you towards a #LifeWorthLiving – for yourself.

YOU MATTER.

SCAN ME

If you ever feel we are not doing any of these things well enough, please let us know by contacting PALS… on 0208… email:
(I cannot find a general PALs number – there are local numbers decided by postcode?)

Signed – CEO and also a Carers-specific lead who will be accountable to overseeing the duty/quality of care, implementation and action plan for Carers as outlined in the Carers Strategy.

GOOD PRACTICE

City and Hackney Forensic Service

- Directorate Family Welcome Pack provided to families when loved one admitted.
- Forensic Social Worker offers family welcome meeting within 28 days of admission and remains point of contact throughout relative’s stay on ward.
- Family therapy service
- Carer support forum facilitated by SW and family therapist
- Open days with service user involvement.

Tower Hamlets Mental Health Care of Older Persons Service

- Individual and/or family high intensity psychological therapy to carers of people with dementia or mental health problems.
- High intensity Carer's Therapy Group soon for carers of people recently diagnosed with dementia
- Carers' session as part of a treatment group for Mild Cognitive Impairment
- We offer psycho-education to carers of people coming to our Cognitive Stimulation Therapy groups

Bedfordshire and Luton Complex Needs Service

- The service facilitates a monthly Carer, Friends and Family Support Group.

Leighton Road Practice

- Carers Champions work an hour a week each on their follow up welfare calls, there is a virtual coffee morning, and the Complex Care Matrons identify carers in the community

City and Hackney Carers Service – Transition pathways

- In City and Hackney the Carers Service works with the young carer's team to ensure that transition assessments for young carers are completed before the young carer becomes an adult. In addition they have implemented a pathway for carers of young people open to CAMHS, ensuring that they are offered a carers assessment prior to their young person becoming an adult.

Bedfordshire and Luton 'I Care' Charter

- The Bedfordshire and Luton 'I Care' Charter with its five principles, co-produced by the Trust People Participation team, Carers in Bedfordshire and carers themselves.

I CARE Charter

5 Principles to aspire to when involving and caring for our Carers

I INCLUSION
- Receiving the right information at the right time
- Being included in discussions to help make informed choices

C COMPASSION
- To be understanding and sensitive to the carers situation and needs
- Providing caring and compassionate support to the carers

A ACCOUNTABILITY
- Communication
- Acknowledging and advising when you are unable to meet a request

R RESPECT
- Treating carers with respect and dignity
- Ensuring carers are not discriminated against in any way
- Communication with carers in a way that is respectful and suitable
- Assisting carers with self-compassion

E EMPATHY
- Put yourself in the shoes of a carer
- Explore how carers are feeling

I CARE
Inclusion, Compassion, Accountability, Respect, Empathy

OUR PRIORITIES

1. Improve identification and recognition of carers including young carers

ELFT believes that carers should be acknowledged as experts in care for their loved one and it is our role to acknowledge this expertise, support and work in partnership with them. While it is important to have a focus on an individual's needs, we need to develop a wider perspective to include their support network as well. This is the right thing to do and supports good outcomes for people using our services. For many people, the services provided by health and social care agencies is a small part of the overall care they receive. It is care provided by their family and friends which enables them to maintain valued independence and relieves pressure on services.

For many people, looking after a relative, friend or loved one doesn't have a name, it is part of everyday life and 'just something you do'. When services fail to recognise that someone is carrying out a caring role this can be a real barrier to assisting carers in accessing vital information, financial and emotional support. This may be particularly relevant to communities where barriers to access already exist.

It may also mean that service providers don't seek to work in partnership with carers and the wider support network and may miss opportunities to hear important information and collaborate in providing best care.

Young carers are particularly vulnerable to being overlooked and this 'invisibility' can have profound consequences for their long-term wellbeing. Many professionals, and even other family members, may assume that children and young people are unlikely to be taking on significant caring responsibilities at home and this is particularly pertinent to adults with mental illness. Research by Dr Alan Cooklin and colleagues has highlighted that children of parents with mental illness are rarely identified as formally caring, but nevertheless take on many adult tasks such as providing food, caring for younger siblings and 'monitoring' the health of a parent.

The problem about being a child of a parent with a mental illness is that the caring is much more likely to be an emotional business. You might also be giving out medication to the parent. You might also be picking up the pieces when a parent has self-harmed or attempted suicide and calling in the emergency services. It is also quite possible that you will not receive any recognition. It is quite possible that it will not be acknowledged that you are doing anything valuable. You might even be blamed or said that you are causing the distress.' (Dr Alan Cooklin 2011)

Professionals are understandably reluctant to approach children to discuss their involvement or to share information but professional curiosity and asking direct age-appropriate questions is crucial. Parents are also often keen to seek support to talk with their children about their illness and the impact it has on family life. The training we will commission will include this challenging area.

Research carried out by Carers UK demonstrates that, by not receiving support at an early stage, the negative impacts of caring are intensified, with many carers missing out on benefits and entitlements and others forced to give up work altogether. A lack of practical help can have a huge impact on health and wellbeing, from long-term physical health effects to mental ill health and social isolation. The longer it takes to identify a carer the more likely it is that carers will struggle without the support and advice they need. A failure to support carers impacts on service users who rely on the resilience and willingness of carers to continue caring.

ELFT is committed to early and consistent identification and recognition of carers across all our services.

- Over half of carers (54%) took over a year to recognise their caring role
- Almost one in four carers (24%) took over 5 years to identify as a carer
- Nearly one in ten (9%) took over ten years.
- Some groups of carers, such as parent carers, young carers, mental health carers and distance carers, take longer than average to identify their role.

By identifying carers, we can:

- Improve outcomes for the person receiving care
- Help carers to look after their own physical and mental health
- Provide access to financial support and entitlements
- Support carers to stay in work
- Reduce isolation and loneliness
- Reduce pressure on health and care services
- Reduce the risk of carers reaching breaking point
- Positively support families and relationships.
- Support carers to continue their studies and remain in education

2. Staff should be aware of carers and trained to engage with carers effectively

ELFT believes that all our staff should be ‘carer aware’ and receive training in how they should be engaging carers effectively. The Triangle of Care sets out how underpinning the effective delivery of services is the ability of staff to listen empathetically to the experiences and concerns of carers and discuss with the carer the best ways of dealing with them.

Staff must be aware of the valuable contribution carers can make to the assessment and care of the service user and engage with the carer as a partner in the delivery of care, someone with expertise and knowledge. Staff must be mindful of carers’ own needs and confident when talking to carers. This does not happen automatically. To help them to meet their obligations, staff need knowledge, training and support.

At a strategic level, carers should be invited to collaborate on the design and delivery of services, their knowledge and contribution recognised and valued. Carers are aware of and realistic about the demands and pressure on services and can offer creative and practical contributions.

It has been shown to be highly effective to have carers taking part in the planning and delivery of training. Staff who undertake assessment and care planning should have received specific training in how to involve service users and carers. This is particularly important in discharge planning, home treatment and community situations which are often reliant on the support provided by carers.

Under the Care Act 2014, local authorities and health bodies in England must work together to support carers, a Carer's Assessment must be offered to any carer who appears, or is likely to have, needs for support.

Frontline professionals and support staff play a critical role in helping people to recognise they are caring and make arrangements for them to have a carer's assessment and to signpost them to advice and information services.

"I wanted to be part of the team. After all, my daughter was coming back home very soon and I would then be on my own. I would have to take over from the professionals." (Carer, Triangle of care)

3. Clear pathways to access support for carers, and help in a crisis

ELFT believes that the experience a carer has when accessing services for themselves or on behalf of the person they care for can have a significant impact on their wellbeing and ability to sustain the carer, cared for relationship. Carers should always be welcomed into services with positivity as partners in care with valuable expertise to offer and have a clear understanding of what they can expect from that service. Good communication and clear care pathways make service users and carers feel valued and listened to.

NICE provide examples of how services can provide carers with information and how supportive pathways can be developed, and ELFT will ensure that our services have available clear and accessible information for carers in several different formats.

Clear communication:

- Leaflets, booklets and online communication which set out clearly; how to access a service; what to expect from that service and who to contact for more information
- Clearly explain any clinical language or jargon and check that the carer understands what is being said
- Consider communication needs, including those of people with learning disabilities, sight or hearing problems or language difficulties
- Not assuming that it is appropriate for a carer to be an interpreter for the person they care for.

Clear pathways:

- Negotiable, workable and understandable for people using services, their families, carers, and professionals
- Integrated so that there are no barriers to movement between different levels of the pathway
- Accessible and acceptable to all people in need of the services served by the pathway
- Responsive to the needs of people

- Outcomes focused (including measures of quality, service-user experience and harm).

ELFT understands that carers need to know that if an emergency happens, replacement care will get sorted out speedily and efficiently. ELFT services will support carers to create an emergency plan and ensure that it is shared with the professional team.

4. Carer voice and involvement

ELFT believe that carers should be included in discussions about issues that affect them, whether that relates to their own care, the care they provide to someone or the services that they use. This includes involving carers in the design and delivery of services at a strategic level, seeking feedback regularly and embedding this across all services. This involvement should be recognised as offering the potential to enhance service design and delivery, carers may see opportunities and solutions which professionals don’t always recognise.

Care and support for the carer:
Carers having a carer's assessment or being provided with preventative care are given the opportunity to discuss what matters most to them, including their own health, wellbeing and social care needs, and work, education, or training

Care and support for the person cared for:
Carers are supported to actively participate in decision making and care planning for the person they care for. Carers are usually the first to be aware of a developing crisis often at times when professional help has not yet been established or is unavailable. They are often best placed to notice subtle changes in the person for whom they care, and usually the first to notice the early warning signs of a relapse or a deterioration in physical health. Carers want to see a collaborative team approach to care and be seen as partners in care.’

Carers want to be kept involved and informed throughout the assessment, treatment and aftercare planning of the person they care for. This is particularly true in periods of crisis and need for acute care, when carers are understandably extremely concerned about those they care for and want to contribute to ensuring that person gets the best care possible.

Confidentiality and information sharing:
‘Confidentiality’ should not be used as a reason for not listening to carers, nor for failing to discuss fully with individuals the need for their family and friends to receive information so that they can continue to support them.
(Department of Health: Developing Services for carers and families of people with mental illness)

The duty of confidentiality is sometimes cited by staff as a barrier to working alongside carers. Service users have a right to expect that information about them will be held in confidence and should only be shared with their explicit permission.

Carers also have a right to share information in confidence and seeking agreement at an early stage about what information is shared between service users and carers can clarify wishes and expectations. If permission to share isn't given, confidential information can only be shared in exceptional situations. In the absence of permission, it is important to remember that staff can still receive information from carers, can provide general information about mental and physical illness and can encourage the use of advance directives setting out the service user's wishes. Permission to share information should be revisited and discussed regularly.

Where permission to share is given, carer views and involvement should be actively sought from an early stage in the care pathway. Carers describe sometimes being made to feel intrusive and interfering by care teams when they either seek information and involvement or offer it. Carers offer valuable information about the person being cared for and will frequently help to facilitate care delivery and act as an advocate for their loved one who may not be able to communicate their needs and wishes fully.

The services that carers use:
Carers should be included in discussions about the services they use to help increase their effectiveness. This is often referred to as co-production. NHS England describe Co-production as a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.

ELFT acknowledges that people with lived experience are often best placed to advise on what support and services will make a positive difference to their lives. Done well, co-production helps to ground discussions in reality and maintain a person-centred perspective.

There are many examples where working collaboratively with carers on design and delivery of services has not resulted in demands which are difficult for services to meet, but instead have produced creative and constructive solutions. This needs to happen in an atmosphere of partnership where honest discussions about constraints and resources take place.

5. Ensure right support is in place for young carers

A young carer is someone under 18 who helps look after someone in their family or a friend, who is ill, disabled or misuses drugs or alcohol. They can be siblings, sons and daughters, grandchildren, not living with the person they care for or looking after more than one person. Young adult carers are young people aged 16-25 with caring responsibilities who are transitioning into adulthood.

The Children's Society have estimated that 800,000 children in the UK have caring responsibilities and 27% of young carers aged 11-15 miss or have difficulties at school due to their caring responsibilities.

The caring role they undertake may not always be obvious particularly when it involves a lot of emotional support or supervision. The role might fluctuate, particularly if the person they care for is a relative experiencing mental ill-health or struggling with drug or alcohol addiction.

Young carers don't always identify themselves as a carer because they see caring as part of their everyday life and something they have always done. Often, they are reluctant to tell anyone about their caring responsibilities. This can lead to young carers becoming isolated and not getting the right support. Being a carer can have a significant and long-lasting impact on a young person's health and wellbeing. Their extra responsibilities often mean they miss out on school and being with friends. It can side-line their whole childhood.

The health of young carers may be affected for a variety of reasons including experiencing stress and anxiety relating to financial or time pressures, exhaustion because of interrupted sleep, and physical injuries from repeatedly having to support or move someone with poor mobility. There is also a risk that these issues might not be addressed if health appointments are missed or not prioritised, or if there is a distrust of health services.

DELIVERY

A Carers Strategy Implementation Group (CSIG) chaired by the Director of Social will be established, composed of staff and carers from across the trust.
The group's purpose will be to oversee and support the trust wide implementation of the strategy via the local delivery plans, ensuring they are consistent with the key priorities and delivered within an agreed time frame. The CSIG will help services identify resources and training needed and receive information about barriers to implementation and help resolve these. The CSIG will report progress to the ELFT Quality Committee.

LOCAL DELIVERY PLANS

All directorates will develop a 'Carers Strategy Delivery Plan' that clearly sets out how they will address the five priority areas set out in the strategy. This is to allow them to account for the specific health and social care landscape in their area and the concerns of carers.

Local delivery plans can be found here: LINK

ELFT WIDE DELIVERY PLAN

ELFT will work with the Communications Team to ensure the Strategy is shared with partners from the local authorities and voluntary sector, carers groups and organisations and the general public.

ELFT will provide:

- Access to co-produced, co-delivered carer aware and young carer aware training in 2022.
- Support for the directorates in the form of central accessible information for carers available in a variety of formats and updated regularly
- Links to local authority carers services
- Annual Carers Survey

MEASURING SUCCESS

The Carers Strategy Implementation Group will be responsible for monitoring the progress of the strategy. This committee will report to the Trust's Quality Committee. The Director of Social Work will chair this Group and report on progress to the Director of Integrated Care.

In addition to receiving regular reports from the directorates on progress of the delivery plans, there will be in place:

- Annual carers survey
- Feedback via PALS and complaints
- Directorates will undertake an annual audit using the '*NICE Guidance, Supporting Adult Carers, Baseline Assessment Tool*' available here: LINK
- Feedback from People Participation lead and Carers Groups