

# Support at Home Report

June 2024

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## Disclaimer

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All the views, opinions and statements made in this report are those of the public who participated in our research across North East Lincolnshire. The report analyses and represents the data collected regarding the experiences of individuals with regards support at home services.



## Executive Summary

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The topic of support at home services is very subjective to those that use these services, as individual packages are very different. This is the aim of support at home as to enable the right support to be put in place to enable the person to remain at home and be remain independent.

Throughout this report there are the comments from individuals around the support at home they receive and their expectations of how this care should be provided, they have shared their honest opinions on the support they receive and if this has enabled them to live independently.

From the support groups to individuals a common thread has been the consistency of carers and that it is important to those using Support at Home and their informal carers to have a regular team. This enables those who are receiving care to build trust with carers and carers learn their preferences etc. this also helps older members of our community feel more comfortable with strangers coming into their home and helps for them to feel less vulnerable. They are aware that this may not always be possible but links into the theme of communication. If changes have to be made, this is communicated to them and a stranger just doesn't turn up, things would work much smoother if this happened. For those who have a diagnosis of dementia this would certainly be beneficial.

The report sets out what those who currently use support at home services and their informal carers would like in the future and to ensure services are robust. Throughout the research the following findings have been identified and the re-occurring themes and trends. Below are the combined findings from all those that shared their views and opinions on the support at home that they receive.

## Findings

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Combining all responses either via online surveys, focus groups, 1:1 conversations and telephone calls the following Themes and Trends have been identified:

### Communication

Communication needs to improve across the system. Those that receive Support at Home and informal carers struggle to communicate with Care Agencies and often feel that nothing changes when they have identified issues. They feel that if a carer is late or does not turn up, they have to ring the Care Agency and try and sort out the issue, then ring Adult Social Care (ASC) to complain, then try and sort cover for other care, especially if they are not local. Carers feel this is a lot of pressure and stress due to the lack of communication.

Some informal carers are still not aware of the services that are on offer within the wider community, from VCSE organisations, more communications of what services are on offer needs to be planned throughout the year so informal carers are aware. This needs to be a multi organisation approach. An information 'Hub' has been suggested with all the

information in one place. The NELC website has a page for support at home on the Live Well site, but Healthwatch North East Lincolnshire are not sure those needing support at home or their informal carers would know where to find it.

Carers being able to communicate with the users of support at home services is important to informal carers. Those that have a diagnosis of dementia or Alzheimer's have differing communication needs and carers need to be up to speed on which communication needs they have.

### Consistent Carers

Those that receive a support at home package and their informal carers are aware that they cannot have the same carers all of the time but would like a regular team that they have built a relationship with. The reason for wanting consistent staff varies from they would know exactly who is coming into their home to carers knowing how to communicate with them. Informal carers would then also not have to repeat themselves, as this informal carer said **“wherever possible it would be the same carers all the time. Things would always be done right and in the best way for my dad. As the informal carer I am forever repeating the same advice/instructions for all new/temporary/substitute carers”**.

### Training of Staff

The training of staff has been raised by all the groups spoken to. The co-production group would like a consistent programme of training in place, so the informal carers know that carers are all trained to the same standard. Those receiving services would also to be assured that carers have the correct training to be able to deal with their individual needs. There needs to be an identified set of standards and a list of essential training that needs to be carried out.

### Timing of Calls

Those receiving support at home and their informal carers understand that an exact time for a call cannot be given, however a time slot could be. **“Carers would stay allocated time; carers would come within time slots allocated or within 2-hour gaps”**. It has been identified that sometimes a morning call takes part very close to lunchtime calls, some respondents said they miss breakfast or lunch as meals can be very close together.

Evening calls can vary dramatically. Those that receive support at home services have said that they can vary from 6pm to 11.45pm. This variation over a six hour period is not what people want as some said they just sit there waiting. Those receiving support at home explained that this needs organising better as if the carers are assisting you to go to bed 6pm is too early and 11.45pm is too late. They understand it may not always be able to carry this out on a personal preference but time slots like delivery slots would be a good idea.

## Care Plans

For those receiving a care at home package and for informal carers they feel that care plans are not being used to their full potential. They feel that they are either not read or not adhered to. Informal carers explained that carers often do not have the time to read them in full or read them at all. They are sometimes also not completed properly and that notes are not left as a way of communicating between the carer and the informal carer.

Informal carers feel that care plans could be summarised better for carers who are not familiar with those receiving support at home. Informal carers explained that this information needs to be easy to read as for those receiving support at home who have communication difficulties or memory issues cannot explain everything to the carers directly.

## Missed Calls

Throughout the different groups and individuals missed calls are the one thing that those receiving support at home services and their informal carers mentioned. A care agency that does not turn up impacts on both the informal carer and those receiving support at home services.

Informal carers feel that if the care agency doesn't turn up then it is them that have to phone and get extra support and chase everyone up. Informal carers asked if there was an early warning system in place if support at home fails? As care agencies just assume that the informal carer will fill the gap. Informal carers feel they have to cancel appointments, social activities, shopping and visits to friends because the care agencies are unreliable.

## Technology

Technology was suggested as solution to ensure informal carers are kept up to date and it was also suggested that care agencies get more 'tech savvy'. An informal carer said, "**needs more tech involvement and tech savvy training**". Informal carers said that a care agency had this facility, but it wasn't used affectively and for those informal carers who do not live in North East Lincolnshire would feel that they are kept up to date with information. Care plans could also be accessible for all those that needed to see it and it would be up to date and a working document. Informal carers could also raise issues through the app and see if care was provided and what time medications were given. Some however were reticent about the idea of technology as they felt it might be complicated, they wouldn't know how to use it or care agencies just wouldn't bother keeping it up to date.

# Recommendations

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## **Recommendation 1**

Information Hub on the North East Lincolnshire Website – this would enable those that need Support at Home and their Informal Carers to go to one place for support, information, advice, and guidance in all matters Support at Home.

## **Recommendation 2**

For North East Lincolnshire to have a mandatory training programme established for all carers so they are all trained to the same standard. This will include what skills carers should have.

## **Recommendation 3**

If calls are missed a central contact number to contact, this will ease the stress on informal carers and allow them to rectify issues immediately.

## **Recommendation 4**

Technology options to be investigated by the Local Authority so informal carer are updated and know when carers have been and what tasks have been carried out, they would also like the option of being able to ask questions through this system. They would also like to view Care plans on this system.

## **Recommendation 5**

Experts by experience to be involved in the planning of future service and to be part of future re-commissioning of services.

# What is Healthwatch?

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Healthwatch North East Lincolnshire (HWNEL) is the independent champion for people who use health and social care services. HWNEL exists to make sure that people are at the heart of their care. We listen to what people like about services and what could be improved.

HWNEL share their views with those with the power to make change happen. We also help people find the information they need about services in their area. HWNEL has the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people. In summary, HWNEL is here to:

- Help people find out about local health and care.
- Listen to what people think of services.
- Help improve the quality of services by letting those running services and the government

know what people want from health and care.

- Encourage people running services to involve people in changes to health and care.

## What is Support at Home?

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Support at home can encompass one activity or several activities and is very much based on an individual's need for service to ensure they can maintain their own independence and continue to stay at home. The initial Care Act 2014 Assessment will assess what is needed, considering what the individual needs and the needs of any informal carer. Informal carers are entitled to a Care Act Assessment in their own right, this includes parent carers.

Care Act 2014 states:

### **Promoting individual Well-being.**

(1) The general duty of a local authority, in exercising a function under this Part in the case of an individual, is to promote that individual's well-being.

(2) "Well-being", in relation to an individual, means that individual's well-being so far as relating to any of the following—

(a) Personal dignity (including treatment of the individual with respect).

(b) Physical and mental health and emotional well-being.

(c) Protection from abuse and neglect.

(d) Control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided).

(e) Participation in work, education, training or recreation.

(f) Social and economic well-being.

(g) Domestic, family and personal relationships.

(h) Suitability of living accommodation.

(i) The individual's contribution to society.

This is why support at home packages are all different and can encompass many activities. The Live Well Website states

"Support at home, sometimes called domiciliary care is provided to people who still live in their own homes, but require additional support with activities, including household tasks, personal care and any other activity that allows them to maintain both their independence and quality of life." (<https://livewell.nelincs.gov.uk/adult-social-care/care-options/support-at-home/> January 2024).

## Why this Subject?

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NELC have approached HWNEL to look at support at Home as it is being re-tendered in April 2025. The project is to assist with what people would like the Support at Home provision to provide in the future and to provide information as to what the New Service will look like and provide for the residents of North East Lincolnshire.

The views of the public will inform the new tender and commissioning process. 3 main questions will be asked; what people receive now, what impact the service has on someone's life and what should it look like/changes that could be made.

The project will involve service users, family and friends of service users and staff of care agencies that provide Support at Home. Their views will be collected either by telephone interviews/conversations, face to face at events and engagement, focus groups, online surveys and anyway that it is convenient for the service user.

The information will be collated and presented to the Director of Adult Services at NELC in the form of a written report.

## Methodology

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Different ways of collecting the information were adopted so that no-one was excluded from sharing their views and opinions. Surveys were used; however, people could complete them online as well as hard copies were available. Also, there was the opportunity to speak to and telephone staff and share their views verbally.

Hard copies of the survey were sent out by ASC to all those that have been identified as needing a support at home service, with the option of contacting HWNEL if they required support or would like to complete it over the telephone.

Groups were attended by HWNEL staff to speak directly to those that use support at home services or their informal carers.

This allowed HWNEL to speak to 404 people and gather views and opinions on support at home services. This was either in-depth conversations or during group sessions. The figures are broken down as such, Curzon Centre 170, Carers Forum 12, Friendship At Home 42, Good neighbours 35 and surveys/one to one conversation 144 - 97 full surveys 47 did not complete fully.

This initial piece of work will be followed up with a co-production event April 4<sup>th</sup>, 2024. The co-production event will allow those who are receiving Support at Home or their family members or friends to help shape the Support at Home Services in the future.



## Limitations of Study

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During this project we spoke to users of support at home service and their informal carers, however we couldn't speak to providers and their staff. Emails were sent explaining the project and links to surveys. HWNEL have received no feedback from either of these groups.

## Focus Group Responses

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### Curzon Centre

The Curzon Centre is a Day Service for older people, provided by the Care plus Group.

The aims of the service are:

- Help people to maintain their independence, by helping them to care for themselves, carry out tasks of daily living and maintain and improve personal skills.
- Provide social contact and stimulation, reducing isolation and loneliness.
- Offer meaningful activities which provide mental and physical stimulation.
- Provide carers with an opportunity to have their own space and time, by offering relief from the stress of caring, support during any health problems, and time for themselves.
- Support vulnerable elderly people with complex needs living in the community.
- Assisting with recovery and rehabilitation after an illness or accident
- Provide services such as hairdressing.
- Promote good health and nutrition.
- Provide opportunities for older people to contribute as well as receive.

<https://careplusgroup.org/the-curzon-centre/> (January 2024)

This service can be provided as part of a care package in place. Healthwatch North East Lincolnshire attended the Curzon Centre on 5 occasions covering Monday – Friday and spoke to 170 people, due to their care needs we did not receive information from all those using the Curzon Centre. However, this allowed as many people as possible to speak about the Support at Home package they receive to Healthwatch North East Lincolnshire.

The following comments were received by Healthwatch North East Lincolnshire, some of those in attendance said they attended the Day Care Centre to give their family a break from caring for them. Others said they attended due to living by themselves and it gave them the opportunity to be with other people.

For some who attend the Day Care Centre they live in independent dwellings in the area of the Curzon Centre. All those spoken to have individual packages of support, some have carers that go in twice a day (morning and evening), some have support from their families, some have support workers, and some have individual PA support.

One lady said that she attends the Curzon day Care Centre but has no other support at home, but she said **“I would like help with cleaning windows”** she went on to explain that she manages usually but it's those jobs she can't manage and needs help with. Cleaning the

inside of windows, she cannot reach and wanted to know how to get support with this. Her family support her but she does not like asking them to do extra than they are already doing.

Another lady explained that she has a cleaner once a week to help her at home and her daughter supports her to attend the Curzon Centre.

Those attending the Day Care Centre also gave HWNEL feedback as to the positive impact the Day Centre has on themselves and their families. One gentleman told HWNEL that he knows that his wife needs a break from him so coming to the centre helps both of them.

Overall, those that shared their views were complimentary about the carers they have, the only less than positive comments were about the time carers spend with them. One lady also said, **“I am dressed by the time the carer arrives as they arrive too late if I’m getting collected for the Centre.”** Other people said that the carers are often in and out and they feel rushed. It was also said to HWNEL that it can be confusing from one day to the next as the times can vary so much.

For this group of people ensuring the carers come to help them get ready so they can attend the Day Centre is the biggest concern. If carers do not turn up on time, then they may not be able to attend the Curzon Centre or they attend but not being dressed appropriately or they haven’t had time for breakfast etc.

**Overall, those using the Curzon Centre suggested that if activities are planned, e.g. the Day Centre then times should be specified in the care plans and adhered to, to ensure that activities can happen and contact with the community can be maintained. Some are aware of their individual care plans, yet others are not sure what is written in them. Easy to read information was also mentioned.**

## Social Club 25<sup>th</sup> January 2024 – Friendship at Home

Friendship at Home is an organisation supporting those over 60 years old.

Friendship at Home say, “We are passionate about improving the quality of life of older people and offer friendship and support to people over 60 living in North East Lincolnshire who may be feeling lonely and isolated. Through the support of our services, we help them to regain confidence and independence so that they can once more become a vital part of their community”. <https://www.friendshipathome.org.uk/>

The group meets monthly and takes part in activities and discussions and enables them to meet as a group so they can feel part of the community.

On the day Healthwatch North East Lincolnshire attended there were 42 members of the group in attendance.

During one of their regular support groups Healthwatch North East Lincolnshire discussed with them the provision of Support at Home and if anybody received it. Some of the members said they received it directly or their husband/wife did. It also gave Healthwatch North East Lincolnshire the opportunity to discuss what Support at Home covers and signposted members to Single Point of Access (SPA) if they felt they needed extra support. They expressed their views on the current service and the support they receive. There was a variety of support provided within the group from 24-hour support to temporary support while recovering from an operation. A gentleman explained that his adult Son was born brain damaged and has required 24-hour care since birth **“We have carers 24/7”**.

A Lady who has one eye and is partially sighted in remaining eye receives support at home from XXX. Explains she previously had multiple carers coming in however, this was causing issues as she explained she did not feel comfortable with this and explained that the carers were not familiar with her, and her needs so were leaving things where they shouldn't be and causing her to not be able to find items and/or trip over. She explained that she called up and advised that if the same carer wasn't sent, she would leave and find somewhere else, and they started sending the same person at the same time every day. The Lady explained her carer comes daily for 30 minutes however this is not enough and says her carer does not feel this is enough either. This Lady relies on her carer to read her post for her, and put cream on her joints and get her washed and dressed etc. Also, carer tries to wash up her breakfast pots for her.

Another Lady explained that she received care after being discharged from hospital, did not consent to going to respite care and was discharged with two physios and two carers. Advised this was exceptional saying they were like **“friends not nurses”**, were kind and built a rapport with her. Didn't treat her too formally, she said **“this is important as I feel I can trust them”**. She said they would **“have a laugh with me”** and **“I didn't feel silly”**. This enabled her to be at home with her husband, who did help a lot but couldn't do everything.

Lady in a wheelchair moved into an assisted living centre with her Husband about 11 years ago. She described that after 11 months, her Husband passed away and she was left living alone. She describes shortly after this; the wardens were removed and that she has carers visiting her. Described the most important things to her about support at home is the **“continuity of care, being able to be familiar with the carer/s as you put a lot of trust in them”**. Reliability and communication, making her that even if something has changed that the person is informed of this.

Another person said, **“people organising don't plan the routes effectively and don't communicate with cared for”**. A member of the group said, **“Carers are not allowed to prepare meals, but can prepare microwave meals”**. This was felt not necessarily to be a healthy option. This resulted in a discussion about healthy options and alternatives to what the group classed as 'ready meals'. A lady discussed an occasion when the Care Agency sent a man for personal care, **“didn't ask if was OK for a male to come and I had to decline personal care. Male carer was fine with this and understood”**.

Other services they discussed as part of their support at home package were Telecare Provider and the trauma/Chronic Care Team. **“XXX are an excellent service, they even ring you to check you’re OK”** and the **“Trauma Team/Chronic Care Team are brilliant had them for two weeks”**.

**Overall, the group felt that communication and building a relationship when receiving care as you must trust the person providing the care are the most important factors. You must be able to trust the person who is helping lift you or helping wash you when you feel at your most vulnerable. This does not happen immediately, and it takes time.**

### Good Neighbours (CPG Group) 27<sup>th</sup> February 2024 – Cleethorpes Cricket Club

35 people attended the social group. The members of the group predominantly live in the DN36 postcode area and did not all receive support at home, however a lot are informal carers so may not currently access support at home but are now aware of the process if they feel things are getting hard. They are also aware that they can speak to the member of staff who helps facilitate the group is from the Care plus group and can help with queries.

The group spoke about general health issues and how they can access support to enable them to live at home for longer, this included services at their GP Practice but also support some have received from the falls team to enable them to feel confident to live alone.

A lady spoke about the support she receives to live independently, she has a network of support to enable her to live independently.

Healthwatch North East Lincolnshire talked about support that was available to them as prevention services and early intervention services to enable them to get support at an early stage. Signposted them to activities in their community.

**The group suggested that more information is needed on what is available within the community and more advertising of small organisations that may be useful**

### Carers Forum 15<sup>th</sup> March 2024 – Carers Support Service

12 people were in attendance and the Carers Forum meets monthly and their aim is ‘To make life better for Carers in our area’.

A discussion was held around their views and opinions on the Support at Home packages their loved ones receive.

Informal carers said that **“there is no point of having anything if there is no Quality Assurance”, “there is no recourse”** this statement was around Care Agencies and how are they checked when providing care in someone’s home.

### Communication

The group spoke about their paid carers and overall, they are satisfied with the care. However it was the main offices they have a communication issue with, they feel when this communication is right the system works better. If they get through to people at the office, informal carers feel they are not listened to.

Communication with regards care plans is non-existence and generally communication between paid carers and the informal carers can be difficult, this was stated by informal carers.

Informal carers were asked if a tech-based system would work for them and help with peace of mind if they are not at home when the carers arrive. The group felt it would be a good idea, however, did raise the question of **“So What”**, what if carers do not turn up and an app on your phone tells you they don’t turn up so what then or you know they have arrived, but they stay 10 minutes, and nothing gets done. **“As an informal carer is the emphasis still on you to contact the care Agency and re-organise it or how do you know what’s been done”**. One of the Care Agencies currently has a digital system, but it never works, and it doesn’t tell you what you need to know.

If an informal carer contacts the care agency, they feel they are not listened to and said, **“I was gaslighted by the Care Agency”**. Informal carers feel they can’t complain as they feel this will have a detrimental effect on the care their loved one receives. They would like to have a central point of contact and it shouldn’t depend on where you live or who carried out the assessment of need.

The complaints procedure is you complain to the care agency, and nothing gets done.

One informal carer raised the issue of when they had contacted the care agency office they gave them lots of personal details about the cared for person, without checking who the caller was. The informal care felt this was a breach of GDPR.

### Training

Informal carers feel there is not a universal training package/standard across the board. They also said that how do you know the training is adequate if it is ‘In House’. Informal carers suggested that training for all paid carers should include:

- Manual handling
- Nutrition & hydration
- Safeguarding – Basic awareness
- Medication
- Health & safety
- CPR

There should be mandatory training for all paid carers, and this should be universal for all organisations, as they feel currently this isn't the case.

Specialist training should be offered for certain medical conditions or circumstances. If paid carers change jobs this training record should go with them, as this would save time getting a paid carer fully trained.

Some informal carers said that the paid carers they have, have said they have requested training, but it has not been forthcoming.

### Care Plans

For those that receive a support at home package, their informal carers feel that care plans are not being read by the paid carers due to them being very long, in some cases. One informal carer said, **“paid carers - they do not have time to read a 25-page care plan, especially if they are covering. Is there a summary version or a quick page, what the person likes/doesn't like. How do you communicate with the service user etc”**. This is more pertinent to when staff are covering, or carers are not consistent. Informal carers feel there should be summary sheet or something like the hospital passport at the front of the care plans that set out clearly the important information and a quick guide to how things should be done.

When the care plans are available, other informal carers said, that the paid carers just don't follow it as they are always rushing. Again, the quick summary guide would also help in this situation as it would make it easier and quicker to read the information so if they are in a rush the person receiving care will still receive the care they need.

### Travel Time

Informal carers felt the current system does not work as carers are not being paid for travel or even given travel time, carers often change the rotas themselves trying to cut down some of their travel time. Some Care Agencies pay their staff per mile and some agencies provide transport, however most of them don't. This then means that those receiving support at home have this included into their care hours.

### General Comments

The Carers Forum felt that there should be more organisations that provide carer to fewer clients as this would solve problems of paid carers having to rush. They are aware that this might not be a viable option, however, paid carers need to spend time with the cared for person. They felt that we need to support paid carers, so they stay in the profession.

As an alternative to this system some have looked at employing PA's, but this cannot be done on the hours allocated and there is no system in place to share PA's.

The informal carers felt it should be a more equal system and not be dependent on where you live or who carried out your assessment.

The carers forum made suggestions with regards communication, training, care plans, travel time and general comments. They have spoken openly about when things have not gone well for them, but they have made constructive solutions to the problems. their biggest ask is that they are part of the solution with care agencies not just to be treated as a fail-safe system, when things do not work. They should not be the ones chasing everyone up.

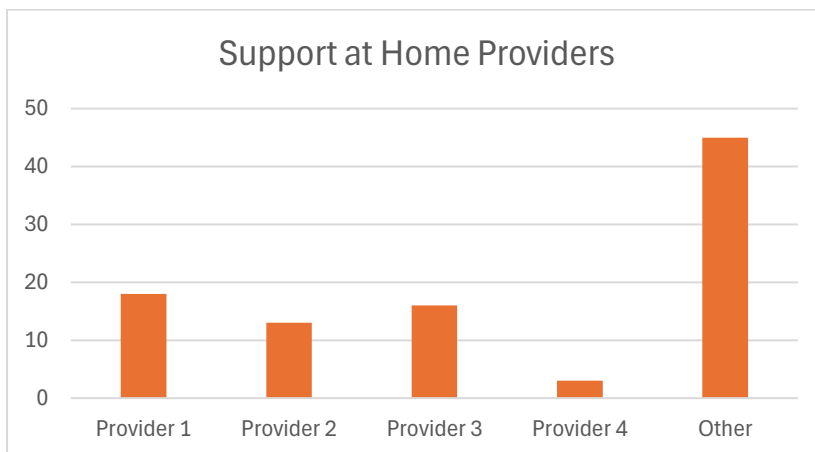
## Survey Responses

The respondents were given the opportunity to provide their responses either via online, telephoning we at Healthwatch North East Lincolnshire or completing a paper survey and posting it back to ourselves via Freepost.

144 individuals shared their views, 47 however did not complete the survey in full or they have clicked on the survey via the electronic method and decided not to participate. 97 completed in full, these responses have been used to collate the statistical information.

### Question 1

#### **Name of the support at home provider**



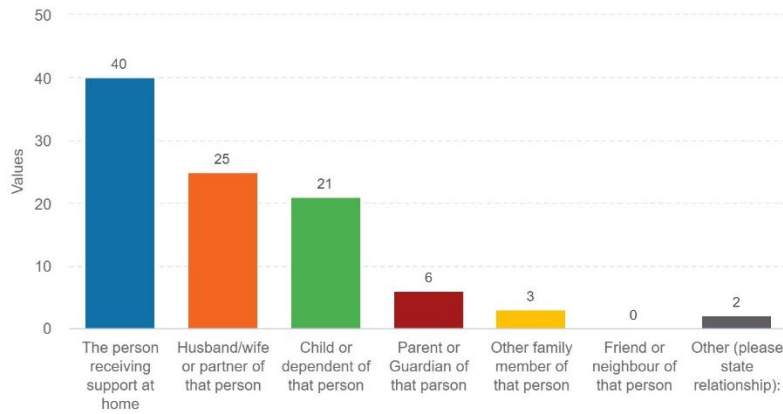
A total of 95 of those who shared their opinions stated which Support at Home Provider they had. 2 people did not want to share this information in case the Support at Home Provider found out who they were, as they felt it may impact on the care they received.

There were 7 other agencies named in the other section as well as people who had a combination of Care Agencies.

Some respondents ticked the other option as they are unsure of who provides the care and support, they need, or they did not specify the Care Agency.

### Question 2

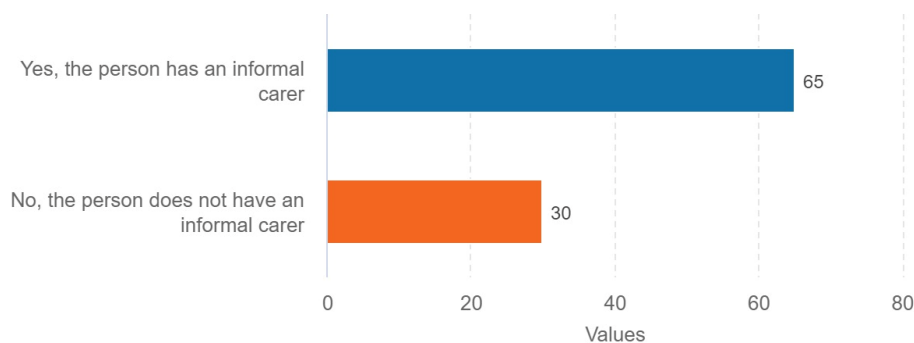
**Are you the:**



97 answered this question, 40 of those that shared their views with us received Support at Home directly. The remaining 57 respondents were family members, the majority were either husbands/wives, partners, or children of those receiving support at home. No friends or neighbours answered the survey.

### Question 3

**Does the person receiving support at home have an informal carer?**

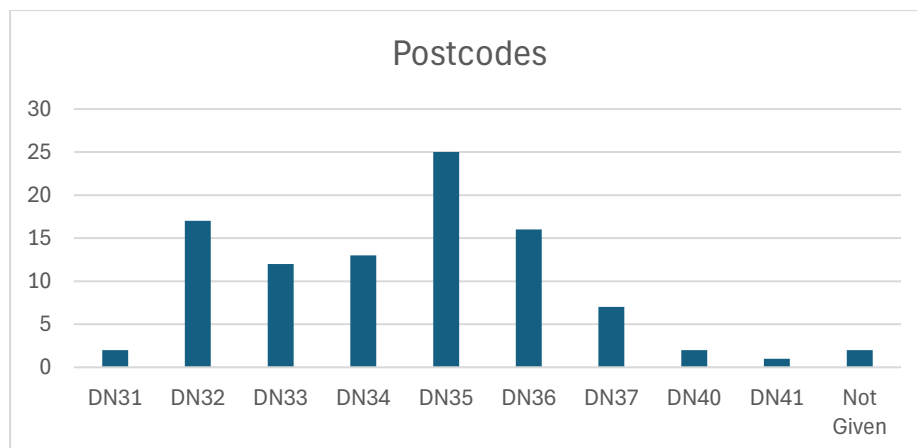


65 of respondents stated that they were an informal carer or that they had an informal carer, alongside the care that they were receiving from Adult Social Care. 2 respondents did not answer this question and 30 stated they did not have an informal carer.

### Question 4



## First part of postcode



Responses were widespread across North East Lincolnshire; however, the lowest responses were from DN41.

### Question 5

**What are your views on the service received from the support at home provider? Please be as specific as you can be. Is the service a morning call, medication call, to give an informal carer a break etc.?**

97 people answered this question, of the 97 respondents, no two support at home packages were the same, support at home packages were designed dependent on the person's individual needs. From the respondents there were those that needed 24/7 care to those that had one medication call per day.

When users of support at home services and their informal carers were asked what your views on the service are received from the support at home provider, the answers were varied and based on their individual experiences. For some the experience of support at home has been positive and helped them to live independently, however for those where it has not been a positive experience they have explained why this has not been the case.

There are mixed responses from those that shared their views.

### Person Receiving Support at Home Responses

Those that felt positive towards the Support at Home they receive shared their experiences with Healthwatch North East Lincolnshire. One person who receives support at home said, **"I would be lost without them"**. Another person said, **"Full time care, excellent service from provider they go above and beyond with very little resources. They fight our corner when social workers keep trying to cut our hours"**. A person who receives support at home said, **"I have carers twice a day and they are really good. I have a morning call and an evening call"**.

For those receiving support at home directly they explained their positive experiences of support at home, **"I have 3 calls a day and I have everything and anything. Not the same**

**person but I have never had someone I don't like". One person stated "Morning Call - shower, dressing, bed making. The carers are helpful and appear genuine in their intention to help as much as needed. Though too often they appear stressed and rushed by extra other people needing help, who they have been asked to help, although they had already had their hours covered".**

This has been a common theme from those receiving support at home that carers seem stressed, and, in a rush, this does not bode well for those receiving care at home. The situation makes them feel that they should not ask for things as this puts the carers under extra pressure.

Some of those receiving personal care gave details of the specific care package they are receiving including the medical needs that they are helped with, **"the calls are to support personal care and administration of medication and to provide support with meal preparation. There is also a shopping call", "morning and evening call for helping to get dressed and washed", "medication visit once a day", "Mon-Fri Mon-Thurs 5 hours Friday 23 hours total a week" and "I have one eye and am partially sighted in my remaining eye, so need help with dressing, washing etc in the morning mostly and putting cream on my joints".** Another person who receives support at home explained that they receive a **"morning and evening for tablets and dressing in and out of bed".** For another person they explained that the calls they receive are for medication which ensures they take their insulin correctly, **"morning/Lunchtime/Tea/Evening Plus 2 medication (insulin calls)".** Those receiving support at home have varied packages including personal care, medication prompts, dressing changes and food preparation. The following is an explanation directly from those that use support at home; **"morning and evening 30 minute call to give medication, food and help with dressing etc", "morning can assist washing/dressing (feet cannot be reached) and making breakfast (toast) and microwaving evening meal (at 6pm) and supervising the taking of medication", "morning call 8am - get dressed, washed and breakfast lunch 12-12.30 tea 4pm bed time 7.30p morning call to give medication", "whatever is required at time of visit. i.e. wash, putting cream on, make a drink" and "4 calls per day for medication prompt, hygiene, help with food and drinks, help with recycling, washing up/making bed".**

Other users of support at home services explained that they have calls to assist with their personal care, a lady said she had carers on a daily basis and that she was happy with the care she received, **"morning - shower daily, Evening - Hygiene care daily, sitters twice a week and happy with the care provided".** For those receiving support at home they praised the carers **"I have carers twice a day and they are really good. I have a morning call and an evening call".** A gentleman said they he receives, **"afternoon calls - 3 times per week to read also take me for a short walk. They provide my wife respite once a week".** An informal carer explained that for his aunt they have a comprehensive package in place which is provided by providers, family and friends and this works for the lady but also the extended support mechanisms around her. The nephew explained, **"Support is given by 1. a nephew, dealing with financial and related matters. also dealing with the company owning the small apartment. 2. friends assist with shopping and personal matters. 3. a**

**third friend with her hair and shopping. 4. the lady receiving the support also pays for formal care with XXX care including hygiene and shower”**

Some of those receiving support at home said they have **“morning calls five days per week, providing washing/shower, dressing and breakfast preparation”** and **washing and dressing etc”**. The following responses were received from those who received a service directly on the support at home, **“morning call to wash”, “I have a morning call to help me get washed and dressed, an evening call to help me get ready for bed. The carers are generally good and on time”, “morning call to assist bathing and shaving, both are satisfactory”, “I have a morning and evening carer and welfare checks”, “there are 4 calls in place per day - morning, lunch, tea and bedtime”, “morning and night time help with personal call. Lunchtime for batch cooking”, “morning 30 minutes call to assist personal hygiene. 15-minute evening call to assist with nightwear”, “excellent service from Support at Home provider Morning and evening calls”, “I have a half hour call by my carer Monday - Friday with an extra 15 mins on a Monday and a Friday. The extra 15 minutes was originally to take a shower but as I cannot get upstairs anymore. I have a full body wash she washes me, washed my hair, changes my bed and gets my breakfast. Others stated, “I have 7 morning visits a week plus 1 evening visit. The main reasons are to help me with personal hygiene and make some breakfast for me”, “breakfast & morning - They look after me well. Lunch - They look after me well. Tea - They look after me well Bedtime - They look after me well Overnight - they look after me well”, “morning call - very satisfactory”, “body wash” and “1/2 hour morning call. 4 days per week - Monday, Wednesday, Friday & Sunday”.**

Support at home services can support people with medical calls and assistance for these people, they explained that they receive calls for medical reasons. It may be a call that ensure they have taken their medication; some people just described it as **“I have medication calls”**. Two other users of support at home services said, **“medication call”** and **“Medication calls”**. Others went on to provide more details one said, **“I have just been in hospital and have people coming in now to see me they are good they make me laugh, check my breathing and everything as I have one lung and COPD and I got a virus so my heart rate was elevated”, “I had the trauma team after being in hospital”** and **“1x30 minute physical therapy call by CHC Funding. 1x15 minute bed call to position in bed to avoid heel sores”**.

Some of those who receive support at home they were non-specific about the care they receive but gave the following comments, **“they come 4 times a day and do everything for me”, “I have support worker and a PA”, “my mum has a carer and mum is my carer I have epilepsy, so the carer helps mum be ok to make sure I am ok. my dad is poorly too”** and **“morning call and medication call. I am still independent to do most of it myself but have a range of health problems”**.

### **Informal Carers Positive Responses**

For those receiving sitter services and/or informal carers breaks they said that the service was invaluable to them, **“My dad has Alzheimer’s, and my mum is his informal carer. XXX**

**come in twice a week on Tuesdays and Thursdays for 3 hours at a time to sit with and care for my dad while my mum has a much-needed break. Overall, the service has been ok, and it's so needed by my mum to help with the caring pressures".**

The informal carers breaks are important to informal carers as it gives them a break from their caring role and gives them the opportunity to take part in social activities or health appointments. an informal carer said, **"Carer sits with my husband to give me a break"** and **"Carer sitter, to give me a break"** and **"A1 staff can't complain I'm in good hands"**. One informal carer explained that she can choose how to have her carers breaks, **"sitter to give me a break, however I choose to use the entire to cover a 6 Hour shift at work, so I know I wouldn't be let down and a sitter would turn up. As it was via an agency"**. Another informal carer explained the flexibility that he and his wife have, this enables him to continue working, **"the support at home can be up to 4 times a day, 5 days a week (Monday to Friday). Depending on my work priorities they also prompt medication and when I am away, will get my wife up in the morning and get her bed at night, as well as meals and toilet"** and one informal carer just said that it was for a carers break, **"carer break"**. Another informal carer said, **"afternoon sit"**. An informal carer explained that they have a 2-week rota system to allow her to participate in activities, **"It's for a "carers sits". 2 x one week, 3 x the next week. repeat 2-week rota. All but 1 evening, other is afternoon - so I can go with daughter to swim"**.

An informal carer explained that they receive an extensive package of support at home and that its **"comprehensive - Care sits 0800- 1730, Monday - Friday. Supplemented by night roving, 2 calls per day AM? lunch/tea on Saturday & Sunday"**.

This gentleman needed respite for his wife due to having an operation for himself and he needed time to recover to continue to care for his wife, he said that he **"asked for help once when I had an appointment at hull Ryal infirmary after an operation. My wife was in XXX care home for a few weeks when I had my operation and for my recovery time. I needed someone to make sure my wife was safe while I was away - approximately 6 weeks"**.

Others explained their positive experiences of their support at home, **"I am very happy with the care given to my wife. They all treat my wife with the greatest respect"**, **"the carer allocated to take my wife for walks, shopping etc is very good"**, **"not bad"** and one informal carer explained that her son has needed care since he was born, **"my son has needed 24/7 care since birth due to brain damage"**.

From the responses received, some people pointed out the things that did not always go well or things that they feel could have been better with a bit more thought or planning.

An informal carer said, **"there have been occasions where a carer hasn't turned up without any notice, or they've switched carer days without consulting mum that has caused additional stress. These have only been occasionally though. I've also found that if my dad gets agitated during a sitter session, they will call mum back rather than try to distract or calm him themselves"**. This does not allow the informal carer to have a complete break from their caring role and they have had to call short certain activities to accommodate this.

The informal carer did not mind at all, but informal carers need time out from their caring role to enable them to stay fit and healthy, both mentally and physically.

This lady explained that her mum is her dad's main informal carer and the benefit of having support at home and the difference it makes to her mum, however the lady mentioned two situations were when it hasn't worked the extra stress this has caused her mum. She said, **"my dad has Alzheimer's, and my mum is his informal carer. XXX come in twice a week on Tuesdays and Thursdays for 3 hours at a time to sit with and care for my dad while my mum has a much-needed break. Overall, the service has been ok, and it's so needed by my mum to help with the caring pressures. There have been occasions where a carer hasn't turned up without any notice by mum, or they've switched carer days without consulting mum that has caused additional stress. These have only been occasionally though. I've also found that if my dad gets agitated during a sitter session, they will call mum back rather than try to distract or calm him themselves"**. Calling her mum back while having her carers break is difficult, the informal carer needs to be able to take a break rather than being on edge thinking they may call her.

### Informal Carers Negative Responses

One informal carer explained that the service is not always reliable and sometimes carers do not turn up, she said, **"Sitter once a week - just had 2 weeks when no sitter available - informed workers although don't always as I feel I'm complaining as it's a free service. Would be happy to pay towards it for a more reliable service"**. Another informal carer explained that initially it was good, and they stimulated her husband, it is not the same now. She said, **"to give the informal carer a break - although started well to stimulate my husband, who has vascular dementia and Alzheimer', this has dropped off. Encourages him to sit in the lounge and watch TV. He then promptly falls asleep"** An informal carer explained that the service they now receive with regards sitter services is brilliant, however they had struggled with the previous provider and that issue of not receiving a service at all. She feels let down by the previous provider as promises were made that never materialised, she said **"the service is a sitting service to give myself, the unpaid carer a break. We have only just started using XXX. They are excellent so far. Previous we had XXX. We were constantly lied to by XXX and gaslighted by them for 6 months. Since May 2023, XXX stated they had no female workers and even lied to the social worker. XXX were also still being paid by adult social care for our sitting service from May 2023, that did not materialise. When I telephoned XXX to find about the sitting service, they always had a scripted response to say why they could not provide the service but stated they had someone available to start next week. Never happened"**.

One person explained that they are not given the choice of providers, this is due to block contracting and the person receiving the care at home postcode. They went on to say, **"XXX is not my choice. They are not good at all, they do not fill posts, they do not communicate well, they do not know insurers details. They are paid to manage; payments are not tended to as they should. Nobody wants back to XXX, we have no choice"**. Another lady explained issues around choice. The carer that had been sent was a male carer and the lady felt this was inappropriate when he was there to carry out personal care. She said, **"they**

once sent a man to do my personal care and I didn't like it. They didn't ask me before if this was ok. So, when the man came and I said no thank you, he understood but it meant I didn't get washed that day and felt horrible".

For other people it was the issue of not receiving what they were supposed to receive where they felt the service had failed. An informal carer said that they received, **"4 calls a day, morning call to get him out of bed is often as late as 12 noon. Supposed to shower and shave but this rarely happens because the staff are not given the time by the provider"**. This informal carer feels that the morning call is too late as her husband has missed the morning while waiting but also it throws out the routing for the day.

Another informal carer said that the carers are never there for the full hour that they contribute towards. She said, **"my mother has 4 calls a day: breakfast, dinner, teatime and bedtime. The service is Ok, but they are not there for the allotted time paid for. They wash her and change her clothes and incontinence pads"**. Someone else said that they had **"4 calls per day; breakfast, lunch, tea and bed time. Breakfast call can be as late as 11.30am. Lunch can follow as early as 12.30. Times are not suitable, carers arrive close together leaving many hours till evening or breakfast"**, for this person the concern was having meals together then a long gap till the next meal. Another informal also said, **"AM & PM personal carer call. personal care is not always provided. Creams aren't always re-applied. Some carers are only staying 5-10 minutes - not sure all care can be provided in this time"**.

An informal carer explained that she also has a daughter who is at primary school and she has to take her to school so if the carers do not arrive at a specified time she has to try and juggle her daughter and her mother, this is difficult and stressful. She explained that **"we receive morning call for personal care. However, I have had a few issues on certain days where this has not been provided or arrived late. Personal care on 2 certain days is at specified times and when this does not happen, I have to rush to get my 9yr old child to school and leave her unattended in the playground. I have to rush back home to tend to my mum and I only have a 10minute slot to do this as she attends day Centre"**.

An informal carer went on to explain that it the not knowing who is visiting her mother that can be stressful, it unsettles her mother and her mother worries if it is going to be someone she does not know. She explained that her mother has a **"morning call to wash and help dress, provides breakfast, lunchtime call for snack and change of pants/use of commode. Afternoon visit for drinks and biscuits, change of pants/use of commode. Evening call for dinner and go to bed, 2 night calls for change of pants. There is a lack of consistency both in times of visits and then carers coming. The lack of consistency unsettles my mother who never knows who is coming and what time"**. She also explained that her mother also worries about what time they will be arriving and just the inconsistency of who and when. Another informal carer also said, **"carers 4 times a day, generally good. Some disruption to the regularity of the carers - i.e. often not the same carers all the time and this has an impact on my elderly dad. The same carers know my dad and his needs/preferences whereas a continuous change of carers and often 'new' carers do not read all the info that is provided to help THEM as well as my dad"**.

The wife of a user of support at home services said, **“Carers do not appear to read the care plan, continuity of time and people is most important to person with memory loss/dementia. This seems impossible to achieve”**. She also explained that due to her husband’s dementia he cannot always communicate to the carers where things are or how to do things. This then causes him to get anxious. For another informal carer explained the issues that occur when the care is provided by carers who do not know her husband she said **“on the whole good except when staff is changed from regular carers. Then there is the timing of the calls goes haywire, occasionally 2hrs late. Too late for xxx as he is getting restless and tired by 7.30-8. We have asked for earlier calls which don’t last so long. There is no consistency as they often get changed. Better communication between office staff and their carers”**.

An informal carer felt the issues she was experiencing around the calls for her dad where due to the provider and not the care staff, she said **“4 calls a day for father, prior to this before my mum passed away 2 months ago, both received the 4 calls plus a through the night call. dealt with company for 2 years and management/office staff are awful. Too many Chiefs! Staff not trained in individual needs of patients. Disability etc., makes the care given hap hazard”**. A gentleman who is the informal carer for his wife also explained that the calls can be very erratic, and the times vary considerably from one day to the next. He said that his wife receives a **“service is mornings - To assist with personal hygiene. Initially my wife needed assistance in actual washing/showering. Since her condition improved, she only requires supervision. Service from XXX - main problem was erratic visiting time 8.30 - 11.30 without prior notification”**. An informal carer said that the calls did not really match the support that her mum needs. She explained, **“morning call should be 30 minutes to give medication and help to shower or wash but come late morning and mum is always up and dressed. Evening call is 15 minutes to give medication. Maybe we need to swap these and have 30 minutes in an evening so mum can have a shower before bed”** she suggested that if the calls were changed slightly then this would provide her mum with better support but felt she is not listened to.

An informal carer explained that the calls her father receives are not long enough for her father to receive the care and support that he needs to get in and out of bed. She said, **“carers are wonderful but call times have been shortened every year by social services so only minimal support can be given in time allocated. Services are morning and evening now, having been cut from 4 calls initially. Calls are to help get my parent out/in bed and support as required”**

### **Person Receiving Support at Home Negative Responses**

A direct user of support at home services explained that both her husband and she receive support with the preparation and support with an evening meal, however the times vary between 5-7.40pm which means they can be waiting to eat. She said, **“my husband and I have home support for our evening meal. the support is fine except for timing. Carer(s) may come at 5pm or as late at 740pm. Also, the occasional untrained carer i.e. wanted to put shredded cheese in the microwave”**.

For a user of support at home services their biggest concern was taking their medication, they explained that it needs to be taken with food. If therefore the morning call is late they are taking medication on an empty stomach. She explained, **“morning, Lunch and tea calls. The service is terrible, I've called constantly about my morning calls. Due to me taking my medication on an empty stomach is now affecting my health. They keep sending carers who have been barred from my house or morning calls don't come till midday”**.

One person who receives support at home explained that it is the worry of different staff and not knowing who will be entering her home that makes her feel uneasy and that you are told to check who is entering but when they are using keys this can be difficult. In her words she explained, **“the people organising the routes don't do this efficiently. They are never able to be on time or give a time. different people come, which I don't like but just accept. but what about for people with dementia, or memory issues or complex issues. surely a continuity of care is important. it concerns me for older or vulnerable people, that they may be frightened if an unfamiliar person comes to their door, how do they know who is safe to let in? how many people should get access to their homes and properties, which such a high turnover of staff all the time it is worrying that all of these people will know key safe codes, or how to access vulnerable people's homes. As cared for we put so much trust and faith in these people, but really with no continuity of care, these people are strangers and there is no familiarity or rapport to be had”**.

A lady explained that again her meals can be close together or she will skip breakfast as the carers come just before her lunch arrives at 12 noon from meals on wheels, she also went on to explain that if the bed time call is late she gets her son to help her instead of the carers. This puts added pressure on her son to carry out a task that carers should be carrying out. She explained, **“I have a morning call to help me get washed and dressed, to get my breakfast and drinks. This should be between 8.30 - 10am. However, sometimes this call is so late that the care worker can only help with washing and dressing because my lunch from meals on wheels comes at noon, so I don't have any breakfast. Recently several calls have been after 11am. I also have a bed call which is mostly OK between 9-10.30pm. Although when it is earlier or later than this my son has to help me get ready for bed”**.

A lady also explained around meals is that the carers can only put meals in the microwave, she explained that she can do that herself, but it is carrying the meal from the kitchen that she cannot do and that is what she needs help with. She said, **“They can't prepare meals, even if they had time. they can only put things in the microwave, but I can't bring it to the table or living room, all they can do is put it in the microwave for me. I can do that myself but I can't carry it”**.

Those receiving support at home raised the issue of timing of calls and that times change on a regular basis. One person said that they are **“always late, I have had to ring them today as they were over and late. I have skeletal spasms due to Parkinsons. I am doing most of what they are supposed to do myself”**. Another person said, **“I receive a morning and night call. The carers (my regular) ones know what time myself and the rest of the round prefer their calls and do them accordingly. XXX office staff alters my times e.g. morning call 11am, night calls can be 5.30pm or 12pm for a night time call. 11am is a dinner call,**



**5.30pm - Tea call.** Another person said, **“XXX - carers are good, timings of care not so good”**.

Another lady who receives support at home, who also pays for the service feels she is not getting the service she is paying for, she said **“I pay for 1/2 hour visit in the morning and 15 minutes in the evening, I never get the full 1/2 hour. I'm not saying that I need one every day, but they never have time for a quick chat. I'm with XXX and if the carers do finish early there's no questions asked. The office staff actively encourage the carers to rush”**. A person who receives support at home directly felt that the communication between the providers office and the user of services is the problem and this makes things stressful, however the direct support she receives, and her regular carers were wonderful. She said **“I have 4 visits per day, morning lunch tea and bed, my regular carers are very good. Their office is unhelpful”**.

**My daughter has 1 1/4 hour per day. this is split between 1/2 hour in the morning and 3/4 hour in the evening. this can be between 7.30 am - midday and up to 11.30pm in the evening. a carer turned up and didn't know my daughter had a stoma or was trained in what to do. They are slapdash and get in and out as quick as they can**

A daughter whose mother receives support at home felt that even though there is a package of care in place her mother often refuses the support being provided and then the tasks fall on her. She said, **“morning and evening they are very kind but mother refuses at times to let them help her, she's 101 years old and a nightmare. I go every morning and take her out, I'm shattered”**. This is impacting on her own health and wellbeing.

### **Those That No Longer Receive Support at Home Responses**

There were some users of support at home and their informal carers that felt having support at home services was no longer appropriate. One gentleman explained **“we initially had a carer organised when my wife left a care Home where she had been due breaking her hip. the carer was organised for a morning call and an evening call. After 2 days we cancelled them as we never knew when they were turning up and we felt like prisoners in our own home. The first call was in the evening at turned up at 8.40pm, the morning call came at 11am and the evening call turned up at 8.10pm. They were supposed to wash my wife and they just wiped her face. the last call they didn't do anything they just chatted. We decided to cancel, and we manage fine”**. This gentleman felt that the care that was being offered for his wife was not adequate, so they decided to cancel the care package and manage themselves. Another lady also had a similar experience as the organised carers did not turn up on a regular basis so they had cameras fitted so she can leave her husband for short periods, she said **“used to have carers but cancelled them, they did not carry out personal hygiene correctly. Sitters were set up when he came out of hospital, but they did not turn up for 2 weeks. I was to attend a funeral and the sitters did not turn up. I have cameras fitted so if I just nip to the shop I can leave for short periods, and I am not sitting around waiting for carers to turn up.”**

HWNEL also received a couple of comments from users of support at home that felt it was too expensive so cancelled the service. One said, **“not applicable too expensive”** and one person said, **“we cancelled it”**.

**In conclusion those receiving support at home biggest complaint was the timing of calls and not knowing who was arriving to carry out tasks that they could no longer do themselves. Also, that they do not feel that providers communicate with them, especially if there are changes that are made to their care plan.**

**Those that receive support at home and their informal carers felt that the service was not person centred but always for the benefit of the Providers, that is why calls were late or did just not happen.**

**Communication is missing across the board, whether it's to change a call time or carer or that calls need to be shorter.**

### Question 6

**What difference does this service make to you or the person receiving support at home?**

There were 97 responses to this specific question both from those receiving the service themselves or their informal responses. There were mixed responses to this answer, some said it that it made a big difference. Others felt that it didn't fulfil their needs.

#### Person Receiving Support at Home Responses

Those that felt it made a difference, felt that it enabled them to stay at home. One said it meant, **“everything, they help me live my life”** and **“I couldn't be without them they make sure I can do what I need to, like washing myself. My legs don't work so they are a lifeline”**.

Another lady said **“My family have said that I can go live with them, but I like my own independence and this way I get that. I have carers come in, I go to a Day Centre a couple of times a week and my family support me as they cook some of my meals and my granddaughter does my ironing”**. For this lady having a combined package of support has assisted her to maintain her independence and access activities in her community, this has enabled her also not to feel isolated.

For a lot of those receiving support at home service maintaining their independence is so important and they want to stay in their own homes, **“helps to enable her to stay at home. Promote safety as checks 4 times a day. less stress for the family”** and another person said, **“a total difference - it would be IMPOSSIBLE to cope without the service”**. Another person explained that support at home services they receive make a big difference to them and said it makes **“a great deal. Independence to enable me to do things”**.

For one person the difference support at home meant to them was that they could be discharged from hospital quicker, and this aided in their recovery, **“they wanted me to stay**

**in hospital, but I wanted to come home so them coming to see me meant that I could come home”.**

The difference support at home makes to the individual can vary and the following comments shows the impact it can make. **“The service makes a huge difference to me as I don't continually worry”, “very helpful” and “It is a great help to me”.**

One lady showed the difference the carers make to her day, as there was an incident were she had tried to get herself ready to be collected for the Day Centre and the carers had not turned up before she was to be collected by the bus, **“they help me to get up and ready and prepared for the day, I do like them to read my post too as I struggle with this, don't always have time to do this though. They can't stay long enough, they come for 30 minutes in the morning, but I do need longer even my carer thinks so. This morning, they were running late, but I needed to be ready to leave for my group as it is my only social outing during the week which helps me mentally. I noticed the difference they make to me when I had to try and do everything myself. I wasn't able to put underwear on, have had to use a blanket as a skirt and safety pin this in place so I didn't haven't to step into something. and I couldn't put cream on my joints, so I am in pain now especially with the cold”.**

The impact the carers make is not just the physical aspects but for her the mental wellbeing is also important, the carers enable her to attend social groups in the community otherwise she would just stay at home.

Another lady explained, **“for me, I lost my husband who was my carer 11 years ago. I was frightened and didn't know how to be on my own without the man I trusted with my life and who cared for me in ways I didn't know how to care for myself. Now I am used to having different people come and meet my needs, but I do miss the familiarity. After a brief stint in hospital, I had a care package in place where the same lady did come for two weeks. and she was more like a nurse than a friend. I think I had forgotten what a difference it makes to be able to build a rapport with carers. When someone I recognise and have met before comes, it makes such a difference to my day”.** For this lady seeing a familiar face and having a conversation can make a big impact on their day and improve their feeling of wellbeing.

The mental wellbeing must be taken into account when also thinking about the support at home packages that a person receives. When a person feels there is nothing to get up for it can impact them in a big way, this person said **“they help me get up and help me get back ready for bed. Sometimes I wonder the point because I don't have anything to get up for. I don't go anywhere. but it is nice to feel clean and ready for the day”.**

For another lady she said **“they were absolutely incredible, they were like friends and family after the two weeks. they even told me ways to wash myself properly which even as a grown woman I didn't know. they were so kind and caring I felt very safe”.** This lady felt that they spent time showing her how to wash herself, this enabled her to feel that she had some control back and could achieve things. This again improved her mental wellbeing and that she was not completely reliant on others.

A gentleman said, **“I am 98 and make me laugh don’t see many people really. I like to put flowers out because my wife did every week, and they help me do this”**. The carers support him to maintain a routine in his life with the flowers to commemorate his wife. They are also the only people he may see some weeks and it keeps him connected to the world outside of his own home.

Another person who receives support at home said, **“without my carers I wouldn’t be able to get out of bed and be able to do the things I like to do. I’m either in bed or in my wheelchair so I need help with personal care, getting dressed and moving from bed to chair”**. For this person they need support with everyday tasks and without the carers they wouldn’t be able to get dressed and out of bed. The impact for this person is in no small way life changing.

A person receiving support at home described what the service meant to them, they said, **“I am unable to do these things for myself anymore, so it means a lot”** and someone else commented that it makes **“a good deal of difference”**. Two other users of the service have said, **“very good carers make all the difference”** and **“it helps a lot”**. For others the impact of support at home is that it **“helps me get ready as I can't do it myself and it saves”** and it makes a **“massive difference as I am unable to do everything myself”**. This user of support at home said that **“the difference in being able to stay in my own home and not having to go into a care home”**, for this person that was the most important thing was to remain in their own surroundings and with the things around them. Another person explained, **“they both support me to go out and do things. I also go to a Day Centre”**.

Support at home services also assists those with medical needs and helps maintain their health and wellbeing. One person explained that the services they receive makes a **“great difference. I struggle sometimes to take my medication and need reminder each morning. I have walking difficulties, so I need to be checked upon”** and another user of support at home services said that **“both calls essential, I cannot use my therapy equipment unaided, and I cannot lift my legs onto pillows at night unaided”**. One gentleman explained that **“my carers are wonderful and help me so much. Service is 2nd to none. carers are pleasant. I did have meals on wheels when I came out of hospital, but it got very expensive, so I have a company that delivers pre made meals that my carers put in the microwave for me. I ended up in hospital due to not being on top of my medication, but things are much better now, especially with support of my carers. The service has made a big difference to my life”**. For this person the combined package of care has helped them maintain a good standard of living and that they feel much better in themselves, especially now the medication is being taken as prescribed. Another gentleman said the difference to him was, **“initially and with the OT assessment it really helped and was struggling after the loss of my leg”**. He now receives a reduced package as he can manage better with the equipment that has been provided and the initial support he received.

HWNEL spoke to a lady who has sight loss and she explained that what some people take for granted is vital for her and she said, **“this enables me to keep up to date with newspapers, magazines and books”**. Some of those receiving support at home packages it also includes maintaining their nutritional aspects and enabling them to have meals either by carers

heating food up or meals on wheels provision. As the comment above one user of support at home felt it was too expensive for them, however, another person said that carers support them to obtain their main meal of the day, **“the support is much appreciated as neither my husband nor myself are able (through mobility problems) to prepare the main meal of the day”**. Another person said that it gave them peace of mind having carers **“peace of mind when husband has to go out, for whatever reason and a friendly face”**.

Personal care was the main area where people felt the biggest difference was made to themselves. A person said that they **“need help with showering had a stroke in March 23 so loss of right side”**. Another user of support at home explained that it is so important in **“maintaining personal hygiene, done by female carers for female person requiring support”** they also felt it was important to have same sex carers as this makes them feel more comfortable. A lady explained that **“I am bed bound so they meet all my personal needs”**. One lady explained that due to the carers assisting her with personal care she feels more like her old self and **“seeing a friendly face and them helping me look after myself”**. Another person said, **“3x 1/2-hour morning calls to get me showered and dressed for the day. 1/4-hour evening call to get me into my night clothes every night. I cannot do these things myself, so these carers are a good help to me”**. For this person this has made a world of difference as it has enabled them to maintain their own personal hygiene but also to remain independent and stay at home. A lady explained that the services she receives makes **“a vital difference as I cannot do a full body wash or wash my hair nor fully dress myself.”** Others explained that support at home makes a difference as they can no longer manage certain tasks and that it **“takes care of personal care”** and **“personal care and meals prepared”**.

### Informal Carers Responses

However, for informal carers the impact of not having to worry about their loved one, is one of the most important things to them and trusted the carers to look after them. **“Feel cared for a secure, never issue whatever help my child needs”** and **“It relieves me a little of the amount of time I go to mum's and also helps mum with tasks she can no longer do”**. This lady explained that the care provided for her mum relieves her stress but also supports her dad **“I'm relieved mum is getting assistance although some of the issues set out above has caused extra stress. The service is good for my dad as it gives him the opportunity to socialise and talk with someone else outside the family unit”**.

Comments from informal carers have been linked to the lack of worry for the person receiving support at home, they feel it takes the strain off them and the stress and they can then also go to appointment, social activities or just clean around the house etc. one lady said, **“it helps to take the strain off me as his main carer”**. Another lady explained that she can't often carry out tasks as her husband doesn't like doing them so when the carers are there, she can carry them out, **“the freedom to do a lot of jobs elsewhere, which he objects to doing, i.e. shopping, tending our allotment, visiting other people”**. Another informal carer explained that due to distance the support at home her brother receives helps maintain his wellbeing and health and enables them as family to know he is taking his medication, **“help as we live in Waltham and my brother lives in Immingham so to this**

**service with giving him his medication helps a lot to know he's getting his tablets every day".** Informal carers also said, **"the service helps me relax and the help regarding putting some washing into the machine or similar help is appreciated"**. A family that we spoke to said that carers provide, **"extra calls to support family care, washing/personal care done by care company"**. This enables them to maintain family relationships but also, so they manage their own lives as well.

Informal carers also stated the difference the support at home service makes to them is that they can continue to work, for this gentleman he has managed to continue to work, however when he goes away for business he said, **"It is great for my wife when I am away a number of days or just for the day. Also helps stop worrying too much knowing the carers will be in regular and will call me if there are any issues"**. Another informal carer also stated that they couldn't continue to work without the support they receive and for her husband to remain at home, **"enables him to be at home, I have to work full time"**. An informal carer explained that **"the service makes a great difference to me and allows me to carry on with work without worrying what my wife is doing. My wife really enjoys the outings"**.

An informal carer explained that it is the peace of mind knowing her mum is taking her medication she said, **"ensures that mum takes her medication correctly, as prescribed by the Doctor. Due to memory loss, she would not remember to take them as prescribed"**. The impact for another informal allowed him to continue with his social activities while still caring for his wife, he said **"the service continues to be very beneficial to both my wife and self. Although I attend to all household activities, shopping, cooking, cleaning etc. I try to keep my own activities going, namely golf for exercise"**. This lady said that the care provided for her dad is invaluable, **"my dad is bedridden. he can feed himself but that it is it. Without the carers I would have gone under, and my dad would be very ill"**. A lady explained that her mum **"didn't like family helping with personal care so it means she is comfortable and in a content mood. Family can remain as 'family' and less so as carers. In this way we help keep her happy and relaxed rather than angry"**. For this family having support at home has helped both her mum and the family around her. A gentleman explained **"as all our friends are now elderly, I need to be assured that my wife, who is very disabled is looked after properly. the person who came was very caring and should I need help in the future. I have every confidence in the staff provided"**. Their friends would pop in and check in on his wife or stay with her while he went shopping but that now is getting too much so they are now having carers, which has supported him and his wife.

A gentleman explained the impact carers have for him and his wife who are parents to son with complex needs, **"my wife and I desperately needed help and support at such a scary time in our lives. my son is now an adult and still receives 24/7 care, and we rely on the carers so much. now he receives care privately from the same team of people who know him extremely well but at first we had carers come in. and having different people come at different times made things very hard because we had to plan our own lives and needs around those carers coming, which with no indication of when they were coming was hard and also we were frightened of leaving our son with a new person who wasn't familiar"**

**with his needs.** For these informal carers leaving their son with strangers was difficult and they also need to build a relationship with carers, they are parents of a child with complex needs, and they must feel secure with who they leave their child with. For another informal carer who carers for their child feels she now needs support. She explained that now she is getting older she is struggling to support her son, who has extra needs. She said **“As I am getting older it relieves the pressure on me doing some tasks, I now find difficult - showering etc. From my son's point of view, he feels good that I am no longer struggling to help him with these tasks as he is very considerate and thinks about what I do for him”**.

We spoke to a young lady who has learning disabilities, and she lives with her mum who has health concerns. She feels when the carers come to help mum, they also help her, **“she makes sure my mum is ok and looks after me too with mum”**.

An informal carer explained, **“I live away from Grimsby and have done for over 48 years. the service allows my mother to live at home in her own house. That is what she wishes. Due to circumstances during Covid my mother did not get treatment in hospital which would allow her to walk again. This required the need of home care Services now”**. For another informal carer the difference support at home makes is that **“Mum could not remain at home as these tasks could not be completed by family on top of all other jobs we do (running her home/shopping/medical appointments/ensuring social activities happen/ taking her out). makes mum less anxious having patterns of regular support. Ensures personal hygiene is maintained, although not good at changing clothes”**. An informal carer said, **“it would be very difficult to keep her at home without the service they provide”**. The person receiving support at home wants to stay at home and with carers support they can do. An informal carer said, **“it means the world! My parent would no longer be able to live independently, without support. provides social contact not just physical support - huge emotional support to client and informal carer”**.

Sitter services are important to those that have a diagnosis of dementia or Alzheimer's or their informal carers. One informal carer said the benefits to her are **“My husband has Alzheimer's and needs 24 hour care, he doesn't sleep at night and can get angry and aggressive. He has hallucinations both visual and auditory. Without getting a break I would burn out and would be unable to care for my husband at home. I have been distraught so often, a proper carer is needed to cater for my husband's complex needs”**. Another informal carer said, **“Carer sitter is to give me a break as it is extremely difficult dealing with a loved one that has early onset Alzheimer's Dementia”**. An informal carer said, **“As an unpaid carer for wife who has complex early on-set Alzheimer's Dementia with epilepsy the sits give me a chance to try and clear my head but gives the wife a fresh face of same sex”**. Another informal carer said, **“mum enjoys the time she has with the care sit. As it gives her some company, someone to talk to and play games”**. Another informal carer said, **“it is my mother who has the sitter that keeps her safe as she has vascular dementia and cannot be left alone”**.

An informal carer explained the differences she had found between one agency and another and the impact this had had on her partner, **“After XXX, we do not trust care providers but XX have been really good. The assessor who visited even indicated that the sitter would**

**help me with tidying up, as I am an unpaid carer for 3 people. My partner is laughing again, they are on time, there is no gaslighting and I trust them. For 6 months without support, it was a struggle, but pleased adult social care listened and got rid of XXX".**

Another informal carer also said that at the start of the process things were not being carried out, but this has now been sorted, **"when the carer arrives, they tend to my mum in a dignified way. A minority didn't do this at the start, and I had mention this to certain individuals. the carer relieves the pressure and stress away from myself, whilst they tend to my mum"**.

Informal carers also commented on how support at home can make a difference to someone's health and wellbeing. Due to carers carrying out personal care the informal carer said that support at home **"makes a massive difference to the person's skin integrity"**. An informal explained that the personal care his wife receives is carried out by female carers and he feels this is better for her, **"it's a great help to her, women are not so heavy handed as men. A lady explained "I would not be able to manage without my morning or night time calls as my husband is disabled"**. Another lady explained that due to her own health conditions she would not be able to manage with her husband and maintain his personal care, **"I am not well myself I have arthritis in my spine so cannot bend pull or stretch so the carers are a godsend for washing and changing XXX. Helps to take the burden off myself. They are mostly caring and pleasant and do the job well to their abilities"**. An informal carer explained that for her mother to have carers come in and carry out personal care it was less stressful and that it **"helps XXX start the day well"**.

### Person Receiving Support at Home Negative Responses

In comparison to those that felt support at home has a positive impact on their lives, some felt that it doesn't impact their lives and can sometimes make it harder. One lady said, **"the carers come in the morning, but they are in and out. I often get myself ready, it takes time, but they faff about and rush me. I don't like them faffing"**. This lady feels that she would rather do it herself than being rushed as the time of her call is not long enough or that they often come very late by which time she has managed to do it herself. Even though a lady was satisfied with her care she did say, **"helpful but timings not suitable at times"**. This sentiment was also shared by someone else, they said **"in most ways it helps but if times are wrong, it makes matters worse as it causes stress and anxiety"**.

Those that receive personal care and have explained that often it does not go to plan so in turn does not make a difference to their lives, it often makes it more difficult have said that it is often due to not being listened to. One person said, **"I am unable to wash and dress without assistance makes me feel vulnerable. Carers don't do anything I ask for and they don't do enough spot checks"**. Another person said, **"if it was well run if should make my life much less stressful. it makes it worse"**. Due to the stress it can sometimes cause with late calls and different carers attending those that receive support at home have said that the difference it makes is **"None what so ever"** and **"No difference at all, I want it reviewing it and they have said I need support. I do fall over"**.

### Informal Carer Negative Responses



Informal carers explained the following about when they have felt it has not made a lot of difference to themselves or the person receiving support at home. A gentleman explained that they had carers come in when his wife was discharged from hospital, however they turned up at lunchtime often and they did not wash her the way she liked it doing so it hadn't made a lot of difference to them. He said, **"It didn't so we cancelled"**. Another person explained the difference support at home made to them, **"nothing that's why we cancelled"**. When another person was asked what difference support at home makes to them, they said, **"Not a lot to be honest"** and someone else responded, **"None"**.

For this lady the support at home is provided for her daughter and even though the care provided is good the lady said, **"my daughter pays a lot for the service, and we never know when they are coming, the evening calls can be too late, and the morning call she is getting her breakfast at the same time as her lunch"**. Concerns were raised around her daughter not having a meal in this circumstance as she would not necessarily want her lunch if she has just eaten her breakfast, this cannot be healthy skipping meals.

It was also raised by one informal carer about the change of staff sometimes leaves her dad anxious due to his diagnosis of dementia, **"dad is 92 years old with dementia and low mobility. Changing people concerns dad, it was set up originally to work around 2 people - but after a month they keep changing the sitter. Dad knows enough that it's a different person, he feels he does everything himself so doesn't understand why they're here. We know by his behaviour - he'll keep looking at the "new person"**.

An informal carer said **"at the moment, not a great deal of help, as the care provided is not giving peace of mind. often the tasks on the carers list are not being carried out, to the point where, on occasion can be a genuine cause of concern"**. Another person stated that they feel things are not provided that should be under the care plan, **"should make a huge difference if it was provided"**. A gentleman felt that he needs more services than is currently being provided and he said, **"would transform my life but I have to struggle on without it"**. Another person felt that the difference it could make if it worked well would be **"when it works means 3 hours of not worrying being able to shop attend appointments etc"**.

An informal carer who supports his aunt feels that housing costs for her to remain independent are not manageable and the service they receive adds to the stress, **"the lady in question has very limited mobility and suffers from macular degeneration, support is vital. the rental costs are unreasonably high, and the landlord company provide no back up support"**.

**Support at home services mean a lot to those who receive services, either directly or for a member of their family. The difference and the impact can vary but the sentiment that runs through the comments is that it enables people to remain independent, in their own homes and gives their families peace of mind. However, for those that the services have not worked for it has been stressful and time consuming and people have felt they have had to fight to rectify issues.**

## Question 7

### **What difference does this service make to any informal carer the person has?**

This question was asked to understand the impact support at home services can make to informal carers. 78 people gave us responses to this question, this includes those that use support at home directly or their informal carers. Out of the 78 people who responded 19 people replied to N/A and 7 people said none. Of the remaining 52 people the following comments were made with regards the difference support at home makes to informal carers.

#### Person Receiving Support at Home Positive Responses

From the perspective of those that use support at home services one person said it **“takes the pressure off my husband as he now has cancer and is limited in what he can do. He has problems cooking and cleaning most days. He also does the shopping”**. A lady said that **“it takes some strain away but can also make this situation more difficult and stressful. My son, my informal carer, has his own physical and mental health problems so is not always able to help with things that are needed when support is not as good as it should be”**.

Those that receive support at home directly are concerned about the impact of caring for them has on their families and in turn the informal carers. One lady said, **“the difference made to my family is to relieve some stress, which my needs must add to their very busy lives”**. Another lady said, **“my daughters do not have to worry”** and another informal carer said, **“my daughter worries about me less as she works and can’t come during the day”** and **“it relieves the pressure on my relative who does not live nearby to make daily visits”**. Those that receive support at home also feel it is, **“less work for them”**.

One lady felt that now her daughter does not have to carry out her personal hygiene needs this has been a big relief, she said **“my daughter and her family also help a lot so not having to help with my personal hygiene needs is a big relief to her, and me”**.

Another user of support at home said that her partner can do other things while the carers are there and not have to worry. She said, **“it means my partner has time to do other things, e.g. paperwork and we can spend quality time together”**. She also felt that because he can get other tasks done it means they can have quality time together. Another person said that **“helps him a lot”**. A lady explained that her husband is her informal carer and that he is unable to carry out personal care, **“informal carer is male so unable to do it”**.

#### Informal Carers Positive Responses

Informal Carers shared their views on the importance of support at home services to them and the impact that it has on their wellbeing. One informal carer said the difference it

makes to her is, **“it relieves me a little of the amount of time I go to mum's and also helps mum with tasks she can no longer do”** and a gentleman spoke about the difference it makes to him, **“as a husband I'm the informal carer that is quite a demanding activity so the morning carer allows me to go out for 2-3 hours in the morning, after attending to her needs for breakfast, medication etc. knowing she can shower safely later”**. For another informal carer she feels if she hadn't had carers she would have gone under, **“I am his informal carer my dad is bedridden. he can feed himself but that it is it. Without the carers I would have gone under, and my dad would be very ill”**.

For the informal carers having support at home packages enable them to maintain their family relationships better and enables them to be a family and not just their carers, one person said, **“this takes the pressure off the family and lets them spend quality time with the person receiving support”**.

Informal carers also stated that having support at home has enabled them to continue in employment and maintain their social lives. One informal carer said that it, **“allows me to continue with work”** and someone said, **“informal carer can continue to work support is invaluable and crucial extra "eyes on"”**.

Another informal carer explained that she can leave her dad for a period of time and go for a swim, this benefits both her physical and mental wellbeing. She said, **“I get to leave him for 3 hours - go for a swim - so mental and physical break for me. I also have long term health problems. I've been having mental health counselling too - but dad comes with me for that and a sitter at the office sits with him.** Informal carers can also carry out other tasks around the home when carers are supporting the person with needs, they have said it enables them to carry out tasks the person receiving care at home.

Informal carers explained that with support at home caring for their loved ones it means they have peace of mind and worry less about them. They can feel safe in the knowledge that their loved one is being cared for. Informal carers said, **“reassurance that my wife is in safe hands”** and one informal carer explained that on occasions he has to work away from home and **“it stops me from worrying when I am away and also when I am worrying from home, as I cannot be available all the time. Peace of Mind”**. An informal carer explained that they felt **“it helps to take the strain off me as his main carer”**. To enable informal carers to maintain working the support at home service is important and again gives them peace of mind, another informal said **“I feel peace of mind while I work that she is cared for and cannot worry”**.

For a sibling carer support at home enables her to feel reassured that her brother is getting his medication as it is not possible to visit every day to ensure that he takes them on time, she said **“help as we live in Waltham and my brother lives in Immingham so to this service with giving him his medication helps a lot to know he's getting his tablets every day”**.

Families also see the benefit of having support at home as often there is an extended family that supports the person, a family said it **“gives family peace of mind and as her daughter and informal carer helps me out immensely, as I live 30 minutes away and still have to work”**. The importance of having a break from caring is important to informal carers as they

feel it gives them chance to re-charge their batteries and clear their minds. One informal carer said that it was important to them to have, **“a chance to get on with bits around the house but also to clear the mind”**. One informal carer explained that with the support at home service caring for his wife **“it reduces the pressure and allows time for doing housework. It helps as when she is happy the day is easier”**. This carer explained that his wife responds better to the carers when they are carrying out personal hygiene tasks and this keeps her calmer and then it makes for a much better day all round. An informal carer explained that support at home enables them **“the freedom to do a lot of jobs elsewhere, which he objects to doing, i.e. shopping, tending our allotment, visiting other people”**.

A daughter explained the benefit that the support at home service has to both her dad who receives the service and her mum who is his informal carer, **“it's an invaluable service for my mum. She cares for my dad 24/7 and without these much-needed breaks she would have reached carer burnout by now and we would have had to put dad into a care home. These breaks are vital to ensuring dad stays at home as long as possible and mum maintains her own health and wellbeing”**. The daughter wants to keep both parents well and healthy and support at home enables that to happen.

With regards the personal care element, informal carers said that **“they are doing the personal care I would have difficulty with!”** and one gentleman explained that we someone else providing personal care, other than him, it **“saves a lot of arguments”**. A lady explained that **“as I am getting older it relieves the pressure on me doing some tasks, I now find difficult - showering etc”**.

One informal carer explained that she now feels that she can leave her partner with carers and not worry. She said, **“I trust the service - XXX. Once you have been gaslighted and start to question yourself, it does affect your mental health. My partner has a serious mental illness, to see him laugh and engage is important. I know I can relax more, know I don't have to rush home and in fact, I can leave my home, visit friends, go to work, go to the cinema”**. Another person felt that having good carers **“gives me some freedom and peace of mind that she is being cared for”**. A gentleman explained that it also gave his wife **“female company for my wife, as I'm her only full-time carer”**.

Informal carers also explained the benefits of having support at home, one explained that it made a **“total difference - it would be IMPOSSIBLE to cope without the service”** and someone else said, **“gives them a life not just existence...they get to live a life and have enjoyment not just sit rotting away”**. Another informal carer explained that being an informal carer can be demanding and the support his wife receives also benefits him, he said **“helps provide respite from the demanding nature of anxious dementia, knowing getting up and main meal is sorted on a daily basis. Some reassurance of safety”**

### **Informal Carers Negative Responses**

For some informal carers they felt that the support at home services received often causes more stress. One informal carer said stress was caused when tasks are not carried out, they then have to do it themselves. She said, **“the fact that basic tasks are not being reliably carried out, this causes stress to any informal carer”**. Other informal carers said, **“it made**

me more stressed” and “helps with personal care and spreads visits throughout the day but also causes stress due to incapability's of company”.

However other informal carers said, “It has relieved some stress away from myself, but I do have concerns when the carer arrives late other than specified time on certain days” and “less stress for family although the care has not been up to scratch at times. Keys have gone missing; medication has not been locked away!”

One gentleman explained that “I was supposed to get a sitter service on a Tuesday and Thursday so I could go and do the shopping. We never used this as my wife is OK to be left as she is a lot more mobile now as she came home mid-February 2024 and can be left for short periods”. He explained that the service could not start straight away and by the time it could his wife was more mobile, so they had no need for it. An informal carer said that the support at home services makes no difference to her as she deals with her husband’s finances. Another informal carer said, “not a lot to be honest”. Lastly an informal carer said that it would make a difference, but they cannot afford to pay for it. She said, “would give massive help and offer respite but I cannot afford it”.

The difference support at home can make to an informal carer is difficult to measure but they have said it makes them feel less stressed and it enables them to go out, visit friends and maintain their hobbies. However, when carers turn up late or do not turn up at all it puts informal carers under pressure, and it often means they must cancel appointments etc. this then means they cannot maintain their own health and wellbeing. If informal carers are to be kept healthy the system needs to work for them as well as the cared for person.

## Questions

**If you could make changes to the support at home service, what changes would you make? How would these changes make things better for the person, or the person's informal carer?**

87 shared their views on what changes they would like to see and why this would be of benefit. The changes that could be made have been categorised to enable analysis of the data.

### Continuity of Carers

This area was raised as those receiving support at home and informal carers felt that having the same carers relieved stress as they knew who they were and felt they would not have to explain how they like things or what their preferences were. However, they are aware that this is not always possible, “I would like the same/few of the same carers but I know that's not always possible. Sometimes it's worrying if someone new comes”. It was also, commented “Having one or a few of the same carers, so that it allows opportunity for familiarity. Also to have more routine in the times they come”. For those receiving support

at home building relationships with the carers is important, **“regular carers rather than random allocation of unfamiliar carers. Regular carers mean relationships/trust and expertise can be built upon”**. Another comment was **“regular /same carer. Being on time”**. Informal carer would like consistent carers for a range of reasons, but the majority of comments were around relieving stress and it would be the best thing for those being cared for. One informal carer said, **“a more regular carer would help relieve stress”**. Informal carers are aware that this is not always possible and as an informal carer explained, **“wherever possible it would be the same carers all the time. Things would always be done right and in the best way for my dad. As the informal carer I am forever repeating the same advice/instructions for all new/temporary/substitute carers”**.

Those that receive support at home and their informal carers stated that this would be beneficial as especially for those with dementia it would help build a relationship and be a less stressful environment. An informal carer said, **“Sticking to the same carers (a comment was made it's not fair to the others (workers) to have the same people go to him - even though they initially got the job agreeing to it in the best interests of his dementia.**

This lady explained why it is important for her to have the same carer, the lady explained to us that she had a visual impairment and explained why things had to be in certain places. **“For them to stay longer and come more often, I really need this. I used to have different people coming, but now the same lady comes which helps me so much as she knows me and the house so well that she can just come in and get on with it. when I used to have different people, it would take them longer because they weren't familiar, and I feel this wasted time. they'd also leave things in places that they shouldn't be meaning I would struggle to find things or would nearly trip over things”**. Another person said, **“Consistency of carer would be good too - this week for instance I have had a different carer each day”**.

One of the reasons why people would like consistent carers is that **“The person would be less frightened and would respond better to the carers”**. An informal carer said **“Consistency of carers, times of arrival and service. This would reassure my mother. She gets very fearful of strangers or late appearances”**.

Consistent staff was suggested as an improvement to care as many felt it would help relieve stress if they who were coming, one lady said **“to have continuity of the caring teams and better time keeping. Obviously, there will be emergencies sometimes - but people should be informed instead of being left to worry unnecessarily”** another comment was **“keep some carers all the time once you got used to a carer they should remain the same. Ones not chopping and changing”**.

One of the reasons people have suggested consistent carers is that they feel reassured who will be coming into their homes, **“a little bit more consistency, I don't always know who is coming”**. Informal carers suggested regular carers so they understand the needs of those receiving support at home as they can sometimes not be able to communicate this themselves and it can help the informal carer during the rest of the day as the cared for person does not get stressed or anxious. An informal carer said, **“regular carers who we get to know, and they get to know my husband's needs. Sometimes ad-hoc carers do not**

**understand his needs, nor do they read the notes which indicates his needs. Consistent times and more or less on time. This can be crucial if feeling tired at night. A 2hr discrepancy is no good". It was also suggested that "I'd like some continuity with the same carers, around reasonable times" and "I don't like it when they change my carers".**

This informal carer explained that due to staff leaving it is difficult for those receiving support at home services, especially personal care. This informal carer did not blame carers, but the care agencies and she said, **"it has taken 7 years to get things running smoothly, a very painful journey at times. If the company cared about their staff they would stay longer, constant changes can be difficult"**.

### **Timing of calls**

As far as the timing of calls is concerned, two main issues were raised is one of the top priorities. The first issue was that people are told they will have an hours call but in reality it is shorter than this.

Some people raised the issue of the calls not being an hour, yet that is what they had been allocated. **"Punctuality, reliability, and training/experience would be my top three changes. The carers often come 15 to 20 minutes late to a session as they are not given travel time and the unpredictability of this can cause issues for mum if she has made plans or appointment and if she struggles to get dad's needs met for a certain time. The reliability point relates to my point above and I would stop sessions being swapped and changed with little notice. I know things like sickness etc have an affect but for a carer and an Alzheimer's sufferer reliability and routine as vital to stopping additional stress and pressure"**.

The second issues were around the actual time of the call and why the time of the call matters and that it needs to be person centred rather than at the convenience of the Care Agencies.

For one lady who uses support at home services, the calls she receives are to enable her to get up and go to bed but she said, **"sometimes when they come at night time they come a little too early to put me to bed. but I do like to watch tv at night and when they put me to bed earlier I can't, but it is ok I don't mind really"**. The lady did not want to complain to the care agency as she was grateful for the assistance but raised as something that could change.

Another user of support at home suggested, **"Knowing what time, they were coming as you feel you are sitting around waiting"**. Someone else suggested, **"Earlier call in the morning like before 9am and evening call after 7.30 I like to get washed and dressed earlier and not be ready for bed too early"**. Another person suggested that calls should not be so close together, **"I would like there to be a more definite time for calls - there is far too much variation. Recently the carer arrived at 11.45 am so my lunch arrived when I was still getting washed and dressed. It would also help to know what time the call will be - the rota I get bares no relation to when carer actually arrives"**. Another person who receives support at home said, **"Timings - coming to give lunch at 2.30pm. Coming to put me to bed**

**at 6.30pm- I sent them away and got my daughter to help me to bed**". This then impacts on informal carers as they are having to take on extra responsibility as this has been arranged but doesn't happen. A user of support at home services said that the carers are **"too often late"**. Another user of support at home services said that's they would wish **"carers would stay allocated time; carers would come within time slots allocated or within 2 hour gaps"**.

One informal carer said **"For the timetable to be specific. It is stipulated the carer to tend to my mum at 8am, this is on her file. However, on the specified days for the 8am call, the timetable was scheduled for 9am, this is when she leaves for the Day Centre"**. Care plans stipulate a time due to things like getting ready for the Day Centre, however this is not always maintained therefore people are missing out on their provision or going but are not correctly dressed etc. This impacts on the whole day as services are not coordinated and communication between agencies has failed. This needs to be more joined up to enable those who are receiving support at home to maintain their social lives.

Other people talked about their own preferences which are not considered. One said, **"I would prefer morning calls at approximately same time each day, and a regular carer"** and another person said, **"mostly it's OK but the time of the evening visit can vary greatly"**. Another person who receives support at home was quite angry that he had got used to a carer and then they left, and this had happened repeatedly. He said, **"make sure that I have regular carers at appropriate times. Get rid of XXX. At least 8 very good carers have left XXX plus another brilliant carer is going to hand her notice in, because of a member of the office team holding a grudge against them and tinkering with their rotas. which has caused me distress, anxiety and affected my mental health"**. Another suggestion was, **"Only more regular timing of morning visits, say for instance 8.30-9.30am"**.

### Allocated Hours

For those that receives support at home services they have allocated hours, some people suggested that there needs to be changes in this area. An informal carer explained that her daughter now lives with them and receives support at home, however when she did not live at home, she received more allocated hours and feels this is unfair. The informal carer said, **"my daughter used to get more hours when she did not live at home with us, we feel it's unfair. training for carers needs to be better"**. Another informal carer said that they provide 24 hour care to her husband but only receives 8 hours of support. She said, **"more hours would be good. I receive 8 hours a week but give 24/7 care which is hard"**.

For those receiving support at home they also suggested more allocated hours or a change in how their hours are delivered. One person said, **"an extra 15 minutes a day so as there is not rushing, which wears me out and usually I go back to bed"**. Another person said, **"a little extra time at the first call (15 mins making call longer would enable me to have a shower or get out of bed earlier"**. Someone else suggested just swapping the calls around **"maybe, changing morning call to 15 minutes and have 30 minutes at night"**. For those receiving support at home just slight tweaks to what they are currently receiving would make a big difference. A conversation just needs to be held with the person receiving support



at home and their informal carers. Communication on a regular basis is the key to support at home working affectively. Another person suggested that if people had their full allocated time proper assessments and caring could take place.

An informal care felt that if carers were not given more clients and their travel time could be cut then the system would work more efficiently. They said, **“If the carer was not given more people to attend once the hours, they were to work were agreed they would be more relaxed and a little more achieved for me. Also, more care in placing clients as close as possible to each other for their carer would save travel time”**.

### Communication

Communication between the Care Agency and the informal carers was raised as an issue. Informal carers feel this is vital to ensure that those who receive support at home are calm and understand what is going on. The relationship between the carers and the person receiving care is important and ensures the day gets off to a good start and an informal carer said that it was **“To ensure the care providing company lets you know if the regular carer is not attending. As they don't and any time away is reduced by 30 minutes because of introducing them to husband and instructing where everything is and what to do”**. Another informal carer said, **“better communication if a carer has gone off sick so you know what time to expect replacement”**. An informal carer felt that the care agency should inform her mum if they are going to be late as she worries. The informal carer said, **“make sure that the company/carers informs mum of calls being earlier/later than planned (for differences over 1/2 an hour).**

For informal carers communication with the carers is also important, they would like an easier way to receive information as they feel current system are not working. One informal carer said, **“more reliable means of communication is vital. Currently a book is in my mum's home to be completed by every carer from XXX - this is often not done and as I live away (In York) I don't have a daily update as to anything that may be required to help my mother”**. Another informal carer said, **“I would like to have some feedback from the provider on how the visits are going or if we can do anything different, to make things better. At the moment I don't receive any reports or have access to carers reports”**.

Carers being able to communicate with those with dementia and having the time to build relationships so the person receiving care at home feels comfortable and not anxious would improve the whole process.

Direct communication with those that use support at home services and their informal carers would alleviate some of the issues and tensions between the two groups. Informal carers do not feel they are consulted but care providers want them to ‘pick up the slack’ (as informal carers put it). Informal carers find it difficult to get through on the phone to the care agency and would like an alternative line of communication in place. An informal carer suggested, **“easier access to phone XXX office. They often say the office is now closed - During hours 7am - 10pm. Also, it would be very helpful if carers had a separate phone number as they cannot contact office if needed sometimes”**. Another informal carer explained that when he must work away the cares are great, however, struggles to get

through to the office. He said, **“It is very good, especially when I am away. They come in early to get her up and do breakfast for her - no changes. Except the office can be very difficult to get hold of by phone and cut off regularly.”**

### **Complaints**

Dealing with complaints is also an issue that the informal carers raised, they feel complaints are not dealt with. One informal carer explained that had not received a good service so had complained to ASC but was still not satisfied. They said, **“I've reported them so many times with XXX nothing seems to get done. need more training”**.

This person felt communication cross cut all the above issues and that communication across the board needed to improve. He said, **“properly run and managed, know who is in charge. Help to make formal complaints with good reason. liaise with service users well and regularly. Give proper paperwork or copies”**.

### **Training**

Informal carers suggested that respite and sitter services need to have personal care elements as often this is required, especially if the person has dementia or Alzheimer's. One informal carer said, **“this service is invaluable, need more provision to help give respite care and able to do personal care if needed so has to be a carer. Not something a person with no training could do”**.

Informal carers have stressed the importance for training with regards dementia and Alzheimer's, informal carer said **“for training and experience, we've found that some carers are much better dealing with dad and his condition than others. Its vital carers have an understanding of Alzheimer's along with how to communicate with someone with Alzheimer's and most of all patience and care”**. Communication skills are important as people have differing needs and different ways of communicating and carers need to have a broad range of skills.

Also, an informal carer pointed out the gaps in training that would support her parent more affectively, she said **“I would certainly make sure staff have more training when I asked a carer what training they had. She told me medication, moving & handling. Health & Safety is a big issue as there have been at least 4 incidents with mum including the door been left unlocked 3 times overnight”**.

It was also suggested that **“to make sure all the carers worked to the same standard. To take more time and use the full amount of allotted time paid for”**. For those that contribute to the payment of their care they feel they should be getting the full hour if that is what their care plan says. One person said, **“it would be great if the calls could be longer”** and **“carers to stay full allocated time for social interaction rather than rushing in and out”**.

Also training to include some of things that show a deterioration in someone's health and wellbeing. An informal carer suggested **“make sure ALL carers know mum's needs/care plan. Carers think 'outside the box' not just do e.g. look for visible changes (e.g. missing**

medication from blister pack not picked - med listed but not in pack). Mum need toilet more as re request”.

### Finance

Those that use support at home services directly or their informal carers talked about the financial implications of receiving services. One gentleman that Healthwatch North East Lincolnshire spoke to explained that he has to pay top up for the services he receives, and this has put him under financial strain at the moment. He said, **“I have to pay top up for the service and this is a chunk out of my pension, so I am going to put it on hold. Reviewing the situation at the moment, my sister is retiring shortly and is so going to move here and look after me”**.

Another person suggested that **“Do not take PIP into account in financial assessment as this is used to fund an informal carer and everyday inflated expenses”**.

Within this section it was suggested that care staff are paid more, and staff would then be more likely to stay if they felt appreciated. One person said, **“I would pay these staff better; I have seen the provider advertise for the roles and the staff are underpaid. It’s a shame as these true carers are life lines to people”** and someone else said, **“give carers more wages”**. It was also suggested that travel time needs to be thought about in carers rotas, some carers have this included into the care hours and it does not allow them to get from one side of town to the other. A person receiving support at home suggested, **“Pay the carers more per hour to improve recruitment and retention. Ensure providers "Build in" travelling time into rotas. At the moment a carer can be given 2 say 15-minute calls on the hour, which may be several miles apart, this means the carer "is behind" from the start of a shift and this makes them stressed and likely to rush or shorten a call”**.

An informal carer did say that they would be prepared to pay more towards the service if it meant the service improved. He said, **“I would be prepared to pay towards service”**.

### Technology

Healthwatch North East Lincolnshire received the suggestion that care agencies need to use technology better and use electronic systems for tracking care better. They said that as, **“businesses they are poor quality and disorganised. Needs more tech involvement and tech savvy training”**. An informal carer asked **“Do XXX have an app where the informal carer can see when the carers have been etc?”**. For some informal carers technology would help them see when carers have attended their cared for person and what support has been provided.

Another person believes that the regulations surrounding care are making it more difficult for carer to do their job, **“Please, please keep these providers going the care rules and regulations are killing the care.... too paper work driven”**. An informal carer suggested that **“somebody astute with authority talks to service users and their staff”**.

Digital option could be provided to assist informal carers to ensure paperwork is carried out, including care plans.

When asked If you could make changes to the support at home service, what changes would you make? For some they are happy with the service they currently receive and do not think changes need to be made. Comments received were, **“Nothing so far, they are very good”** and **“My carers are great and the service work for me”**. One lady said with regards the care her mum receives, **“Nope, the care she receives is really good, she keeps her company and helps with changing her bedding and doing her washing. she also sits and plays dominoes which my mum really enjoys”**.

Three respondents said **“None”**. Other respondents added to this statement, **“None, they were amazing”**, **“N/A”** and **“None, the services is second to none”**.

A person who receives support at home said, **“Nothing they are Grade A five stars sometimes someone comes who is more inexperienced, but I am just grateful and know everyone has to learn”**.

Others said that **“No changes necessary”**, **“No changes, knowing when they are coming helps me, they come at the same time every day I like a routine”** and **“No changes”**.

Finally, comments received with regards if they wanted anything changing are **“Happy as things are”**, **“The care is perfect as it is”**, **“I have a good combination of things so between it all I have what I need”**, **“The service we receive is good”**, **“Can't think of anything”** and **“The support is adequate for my current needs”**.

In summary the changes that were suggested is with regards communication. Communication across the board needs to be improved and a way of sharing information more affectively needs to be established. Whether this a digital option or a more coordinated option, it needs to be implemented. When communication is good between informal carers and care agencies then less problems arise.

Issues with timings of calls also stems from the lack of communication. If a carer is running late or is unable to attend this is not communicated to either the person receiving the support at home service or their informal carers.

Training for carers need to be specific depending on who they are caring for. Individual needs are often not considered.

## Question 9

**Does the support at home service help with other tasks such as shopping, washing, or cleaning?**

86 people gave Healthwatch North East Lincolnshire direct feedback with regards Care Agencies helping with any other tasks. 9 didn't answer the question, out of the 86 respondents 28 respondents just answered no and 3 answered yes.

These answers varied and for some of those receiving these services they are paid for separately and for some they just receive what they have been assessed as requiring. The responses have been separated into three areas; yes, no and informal carers provide this support.

### Respondents Answered No

The comments that have been categorised as no; respondents have given an explanation. One person said, **“It should but I can't afford it”** and another person said, **“They don't have time; they can only just manage to meet my physical and health needs in the time they have”**.

Some respondents said that they have private arrangements for some of these tasks, **“No, separate cleaning arrangements”** and **“I have a private carer 4 days a week and receive carers from support at home agency 3 days per week and to cover holidays etc”**. Another lady said, **“I do have a cleaner for 1 hour a week”** and another person said that the **“paid care helps with washing clothes/bedding. I pay for someone to clean”**. Another person receiving support at home said, **“at times but normally this is additional service we pay for separately”**. This lady pays for additional services separately from the support at home package she receives so she can maintain her home.

Others replies were centred around the carers only do what is stated in care plans, **“No, they won't do anything above what they are supposed to do”**. One lady who receives a sitter service for her mum said, **“No, they just occupy my mother with TV, garden, making cups of tea and making sure mum eats lunch”**. Also, **“No. just emptying the catheter and providing any meals, which I provide”**.

For some of those receiving support at home they felt that if they asked carers would probably help them with other tasks, **“No but I think they would if I asked them to and they had time”** and someone else said **“No but will occasionally wash up”**. One lady explained that they have a sitter service for her dad, and he does not have personal care however **“No - they do provide personal care if needed so if dad has a toilet accident they will assist”**. An informal carer explained that carers prompt her dad **“They ask him to have a bath twice a week while they are there”**.

A couple of those receiving support at home, who are supposed to receive these services said, **“Washing should be done - but isn't. Shopping if needed - this too has never been done”** and **“The normal carers don't clean after themselves. leaving butter out to go off, not emptying recycling boxes so overflowing, not putting washer or dishwasher on until I've got no clean clothes or pots left”**.

For those who receive support at home directly their responses were **“No, my family do it”**, **“No, no other services is required family does this”**, **“No daughter does that”**, **“My family do shopping etc”** and **“I (daughter) do the shopping and washing”**.

One lady said that **“Daughter does shopping and has it delivered”** and **“My daughter does my shopping”**.

One lady explained that her partner does all those tasks as she is unable, she said **“No, my partner does clothes washing, shopping and cleaning”**.

Informal carers said, **“Shopping. Domestic support is provided by myself and my sister”**, **“No, I do it all”**, **“No, I do all the washing and cleaning, shopping. Also, I give her all her food, drinks and medicine”** and **“Family do shopping”**.

Other comments received were, **“No, I am able to do that”** and **“No, I do all this”**.

A lady explained that due her husband’s dementia it can be difficult for him to receive help and support from others, **“No - I have usually set everything up, especially his toileting - sometimes he gets a bit defensive if someone else assists as said before (doesn't question me assisting 99.9%). He feels he can do it all himself, but reality has very often proved otherwise, when he has tried to do so”**.

For some this support is provided by their Personal Assistants (PA’s) or they are supported to carry out these tasks by their personal assistants or Support Workers. They said, **“My PA and support worker help me”**, **“The girls/PA's help with shopping and personal care. XXX were also doing some tasks where PA posts are not filled a year later”** and **“No got a PA for that”**.

### **Respondents Answered Yes**

For those that answered yes said that this is often not a formal agreement but a more ad-hoc support and only if time allows. They said, **“If they have time they will help”**, **“Sometimes they will clear my few pots and tidy the kitchen if they have time they are very good they do try their best to do as much as they can”**, **“Sitter helps but no formal arrangements are in place. We have XXX”** and **“Time does not allow much more than my personal support to be achieved. Washing put in the machine or that finished previously put to dry, but time would not allow much other achieved”**.

Other respondents said, **“yes – cleaning”**, **“yes, she ensures my mums bedding is done every 2 weeks”**, **“yes, on a Tuesday of every week and carer goes shopping for me”**, **“shopping”**, **“washing”**, **“washing up, making drinks”** and **“yes, they help me with everything”**

Others described that the extra support they receive is part of their care plans, one person said, **“just the washing and drying which is a mutually supportive endeavour between XXX and me”** and **“yes. Cleaning and tidying from XXX, has been identified as a need for my mental health”**. A lady explained that due to visual impairment she needs support with reading post etc. She said **“reading my post. I need large print and use a magnifying glass but still find this difficult, so the carer reads my post for me if it comes in time whilst she is here. This is really good when for example last week I had a letter about an urgent hospital appointment, and she was able to tell me about it. I could have missed this otherwise”**. For this lady the support she receives may seem minor, however the impact for her is large. Without this support she would not be able to ensure she attends medical appointments or be aware of other important appointments or documents.

For those receiving support at home or their informal carers they felt that it was a time issue as one gentleman said, **“when my wife is asleep in bed, they sometimes do some cleaning”** and **“sometimes if they can”**. Other people said that if they ask the carers, they will do it, if they have time. One person said, **“Hoovering upstairs and will help me get the washing out of the machine if I ask them”** and someone else said, **“they wash the pots and have done washing when I am away and even ask if anything needs doing”**.

A lady who receives support at home explained that yes, the carers do the basics and they will tidy up a bit however they do not do any housework and she feels that it is not looking tidy now. She said they, **“help with basic tidy up/washing up but no housework. The house looks untidy”**.

One informal carer explained that carers only do what supports the individual who is receiving support at home directly, they understand this but often means separate meals must be prepared etc. He said, **“Only that which directly supports the service user - all my own I am responsible for”**. Another informal carer said that when it is different carers her mother will not let them help or doing any extra. Her mother has a diagnosis of dementia and she said, **“yes, cleaning when mother allows it!!!”**.

One gentleman explained that the carers help him with flowers once a week as it is a way he remembers his wife, and this is a tremendous support to him. He said, **“yes, everything and my wife’s flower to help me remember her”**. This shows that support at home is not just about personal care, it is what is considered the little things that can make a big difference in a person’s life.

**Those that receive support at home and their informal carers explained that the chats and the relationship that they have with their regular carers helps them feel connected to the world and it is important to have contact with people as well as support with personal care etc. consistency, being listened to and support is all they ask for.**

### Question 10

**Is there anything else you would like to tell us about support at home services?**

72 individual responses to this question were received, out of those 70 responses 16 people either said they had no comments or said, **“No. Happy with the service they provide”** and **“No. very happy with the service provided”**.

Those receiving care and their informal carers have gone on to explain when issues have occurred and shared their views and opinions on how this had made them feel. Suggestions have been proposed on how mistakes and issues could be rectified in the future. The issue of staff training has been raised several times and the communication with Care Agencies.

### Staff Training

Staff training was an important issue for those receiving support at home but also for their informal carers, who have trusted someone else to take care of their loved ones. **“Carers should receive thorough training given the levels of responsibility, "shadowing" someone for a couple of shifts is inadequate”**. Another person said, **“Staff should be fully trained, including how to tend to a person who is incontinent and does not know how to look after themselves”**.

Another suggestion was that **“Apart from the odd one or two the carers are lovely, but I want to add that they are very young and have not been to the university of life. My suggestion would be that they worked for a diploma of some kind maybe at different levels to qualify as carers. So, they can learn about the illnesses of old age and how to deal with them i.e. Alzheimer’s arthritis and hydrocephalus. They could also be tutored in how to empathise and sympathise with the elderly and talk to them. Also be trained at the highest level of washing showering by following good practice”**.

### Communication

Communication was raised as an issue **“We were disappointed that when we got mum home the carers were to start the next day and due to staffing issues, nobody turned up. A phone call would have helped under these circumstances”** and **“Being able to contact people when things go wrong and to receive assurances that problems will be rectified. A number of times it has not been possible to get through to XXX”**. Another person said, **“communication can be poor when there is service disruption i.e. carers may be re-allocated last minute”**.

Informal carers wanted to say that often trying to get through to the Care Agency by phone is difficult, especially when carers have not turned up or if informal carers are not sure who and when carers may be turning up. One person said, **“understanding care agencies have to make a profit to run their businesses - but some leave a lot to be desired. Trying to contact them by phone is hopeless Very few seem to know what is going on sending people who are not trained or capable of doing the job”**. An informal carer explained that the issues that they have had is due to lack of communication between themselves and the care agency. He said that things are, **“generally OK now, but I never feel I can’t totally rely on it as I do get glitches that could be avoided, if communication was better. Poor communication has caused most issues - this shouldn’t have been the case”**.

A person who receives support at home services explained that she feels communication has failed and that she has not been listened to. She explained that she had raised concerns and that her care plan had changed due to her needs changing and a new plan was agreed, however, she feels that they couldn’t provide it for her so went back to their original plan. She said, **“when various bodies agree with what you have told them and the "plan" going forward, that they suddenly kick back to their "own regular covers all plan". so, appear to listen etc. then this often happens. When asking for help i.e. "what else can I do", don't give the answer ‘what do you want me to say/tell you’ When you're struggling i.e. constant pain in legs”**.



A lady who receives support at home services explained that there is a **“lack of communication, no empathy with office staff, no complaints followed through. Staff need to be retrained; some don't know how to cook fish fingers”**. She feels that there is a lack of communication but when you ring to complain she is not listened to and ignored, this does not improve the services she receives. This lady was not the only one to raise concerns about the complaint’s procedures. Another person said, **“I have made complaints to the company two weeks ago about some of the evening calls times being really late”**, she went on to further explain that nothing has changed.

### **Complaints**

An informal carer explained that she has made complaints and finally ASC is looking at changing the provider for her mum as she feels the care was not up to standard. She told us, **“I have put in numerous complaints. I am waiting for XXX to change service provider. As I became stressed and emotional when I had no-one to turn up and my mum went to the Day Centre unwashed, and she is unfortunately double incontinent because of her condition of dementia”**. An informal carer raised an issue that she felt the care her mother was receiving was not up to standard. She said, **“On at least 2 occasions my mother has not been given her medication. Mouldy food has often been found in the fridge and she has received little or no help with dressing. This is mainly due to the fact that the carers have far too many visits to attend and therefore the timing of visit is unreliable. A service which was set up by XXX after my mother was in hospital has caused a very high level of concern”**.

Another informal carer explained that she has complained several times to the Care Agency and feels that nothing is being done and that her elderly relative should have a right to choose carers and providers. She said, **“XXX are employing staff that copy regular carers notes, as if they were their own. When reported nothing is done. These notes are a legal document that could be used as evidence, if necessary. Also employing staff that cannot understand the English language and sending them to a 92 old lady who is bed bound, when complaints have been made service users have been told they cannot ban them from their house. This is disgraceful”**.

A lady said that she finds complaining difficult as the Care Agency has previously told her that she was getting angry, when she explained that she was upset and couldn’t explain properly, she went on to say, **“Complaining is difficult as they feel I am angry, and I am just upset”**. An informal carer believes that the office team at the care agency try to cover up complaints, so they do not have to report them through to ASC. The informal carer also said that the carers are not match properly with the service user. They said, **“office team lie to cover any complaints and not sympathise at all. carers need more thorough training and better allocation to service users. Social Services little or no help with ongoing problems”**.

A lady who receives support at home explained that she wanted to change care providers but said it’s **“difficult to change company offering care. Nothing has happened after many requests”**. She said she now feels let down.

## Timing of Calls

Those that use support at home services directly or their informal carers consistency was again raised within this question. An informal carer explained that they are aware that money and costs involved in support at home services is high however said, **“I know so much comes back to money and costs involved but for this service maintaining consistency, and reliability is vital. This service is much needed support for us as a family”**.

Informal carers and those receiving services also explained why consistency of times of the calls is important. One lady said that she, **“was recently unable to attend a funeral as no sitter and was only informed 30 minutes before due. Dread ringing workers - feel like being a nuisance which is why I don't always get in touch. I am grateful for the sitters it's great when it works but has a massive impact when it doesn't - I no longer arrange Dr appointments when they due as if late or a no show it's too stressful I now pay someone to come on those days. - I do appreciate there will be staff sickness that means no one available”**. This caused her a great deal of stress and now has had to sort out private arrangements for those essential things for herself like doctors' appointments to ensure she can attend.

Other people explained they understood that there are staff shortages now and recruiting carers is difficult and that they understand why time must be cut short. One person said, **“I think they do a great job for poor pay. They often can't spend enough time with the person some tasks care left unfinished due to time constraints”** another person commented, **“I realise there are staff shortages and carers are poorly paid for what they do but still think it could be better organised”**. A person who receives support at home said, **“The Home Care Services need more staff to cater for all the clients. that is the reason the carers are always in a rush”**.

## Choice

Choice is the main thread that runs through this section. Those that use support at home services want a choice of providers and this would improve standards within the care sector. They said, **“I consider service users should have a choice of provider, rather than being tied to the provider who has "secured" the Local Authority Contract in particular locality. This would encourage competition and drive-up standards”**. Another person said, **“I would like my care to be handled by one care company. I would like that to be XXX as my family has most contact with them and they know me best and what I like and need”**.

An informal carer said, **“we have only been with XXX for a short while. They have been transparent and reliable. Communication is good. Constantly ringing and chasing like I did with XXX was clearly a sign of their negligence and nothing was person-centred”**.

## Transport

An informal carer raised the issue of transport and that due to changes made he can no longer access shops, which were an important part of his respite. He said, **“the local shops were important as they provided essentials but also a break from the house. The buses have been withdrawn/ re-arranged meaning the shops aren't accessible. This is important**

as only M&S are available via a bus and we have no public transport to a Doctor or Dental services now as well”.

### Positive Responses

Within this question some of those receiving support at home and their informal carers wanted to point out things that are working well for them, one person said **“there is also Curzon Day Centre and Admiral Nurses helping us. The rota- sent in an email- is very useful Dial-a-ride service doesn't work well for us in our situation”**. For this person a multi-agency approach has provided the services they need, in a person-centred way.

A person who receives support at home wanted to say about the future, **“the support we receive at present is good but may change but in the future as my health etc changes, but I feel confident this will be taken into consideration as & when necessary”**.

Those that receive support at home and their informal carers mentioned the benefits to themselves when receiving services. An informal carer said, **“this service is invaluable to my health and sanity. My husband's condition can be so unstable without this respite my mental health would suffer, it's hard to give my husband the care he needs with broken sleep as it is. It really is 24 hours care he needs”**. Another person said, **“It is a valuable service, which helps me maintain a better quality of life. Things would be very hard without the care I receive”**. One of the biggest benefits for people receiving support at home is that **“I can stay in my own home”** and that it is **“Overall, utterly marvellous and could not stay at home without their valuable support.”**

Some people wanted to reiterate that the support they receive from their carers is excellent and the carers do a good job, **“All the girls are professional and efficient and treat my wife with greatest respect”**. Another person said, **“I am grateful the carers exist. God bless them”**. Also, **“The carers I have and like are very good and cheer me up half the time”**. There were further comments, **“They are professional, helpful and cheerful”**, **“I go do nothing but praise my 2 regular carers, they are 'angels' but they are so busy, it is off to the next job”**, **“very good”**, **“the service is good”**, **“the carers I have had to help me have all been kind and helpful and pleasant people”** and **“the attitudes are very good in all staff that I speak to. I am usually able to get changes to call times for appointments”**.

Others wanted to praise the service they receive, **“we really appreciate all services and assistance provided, especially in earlier stages when wife was very unwell. It continues to be very beneficial in many ways”**, **“we have had excellent service from the team providing safety, help around the home”** and **“It is a very valuable service much appreciated. I have gone from 30 hours health professional to 12 hours per week. This has had a huge financial impact to myself and this service is invaluable”**. One provider was mentioned by name, **“XXX offers a very valuable service and gives me peace of mind that my brother is being well cared for”**.

Lastly in this section an informal carer said, **“do you have people who just visit for a chat, she(mother) won't go to clubs etc, but she gets fed up being alone a lot. She did have a visitor, but she only came when she felt like it, instead of a set day, which would be good**

**for mother”**. Unfortunately, this was from a survey that was completed online, and the respondent did not leave their contact details for us at Healthwatch North East Lincolnshire to follow up. It may be worth considering general communications on social media etc. of things that are on offer in the wider community so informal carers know what is on offer, not just through statutory agencies.

**In conclusion people would like communication to improve and for more choice of times and services provided. More importantly they would time and considerations. They are aware of the cost of services and the shortage of carers within this sector. However, the impact on these individuals can be stressful and means they cannot maintain their independence if carers do not attend or are only at their homes for a short period of time.**

**They would also like more choice of providers and better complaints procedures in place, they are complaining to the provider, but they feel they are not being heard.**

**Those using support at home and their informal carers feel that when services work well, they receive the support they need, however, when things go wrong there are not contingency plans in place and they do not end up with a service at all.**

## **Staff Responses**

Staff who work within Support at Home Services were given the option of completing an online survey and/or contacting HWNEL to express their views and opinions. These surveys were shared across Support at Home Agencies and social media. HWNEL received zero responses.

The staff/volunteers at the Curzon Centre did share their thoughts with staff while staff attended the Curzon Centre. Volunteers/staff said that some of those who have carers in the morning, the times can vary enormously. The carers may have got to them very early so they often go back to bed after they have called. It can be confusing as they do not know when the carer is coming and there can be a time difference of 2 hours from one day to the next.

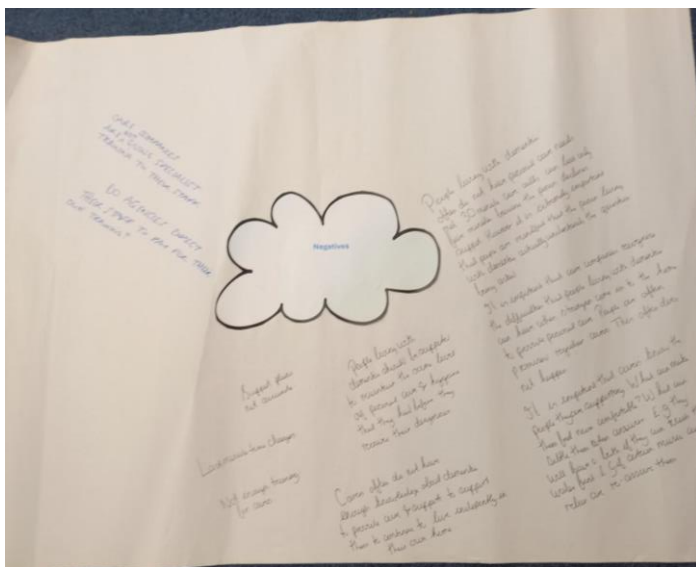
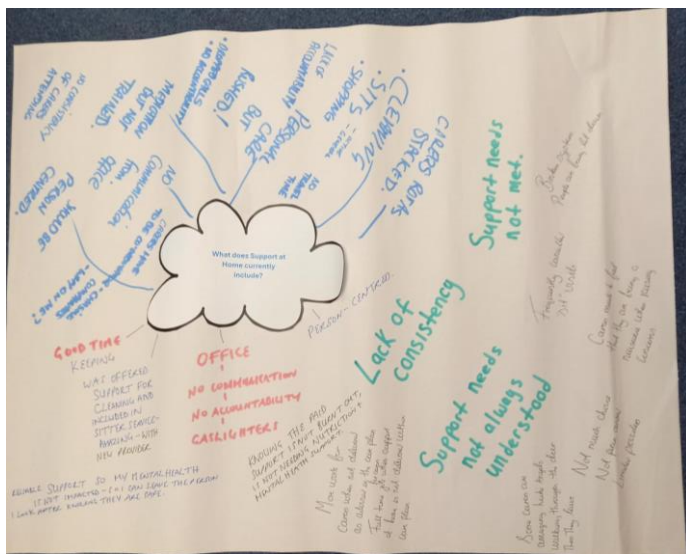
## **Co-production Event 4<sup>th</sup> April**

Informal carers and a member of the Alzheimer’s Society were present. The group came together to work in a co-produced way to design what the Support at Home should include and what it could look like in the future.

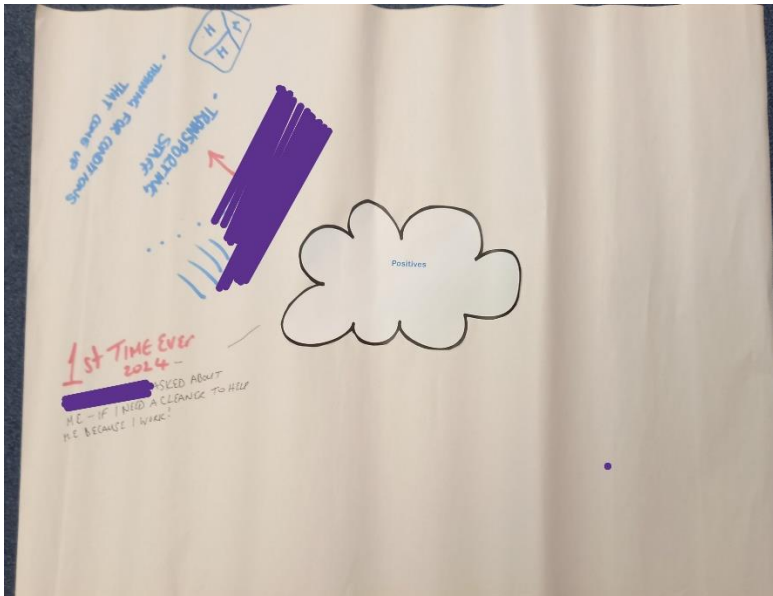
The group first looked at what the service looks like now as a baseline for their discussions.

**What does it look like now? (Including Positives & Negatives)**

The group when working on this question could not separate some of the issues with the current system so have included this information as well. The group started with this so they could clearly define what also worked well and what didn't work so well.



Negatives

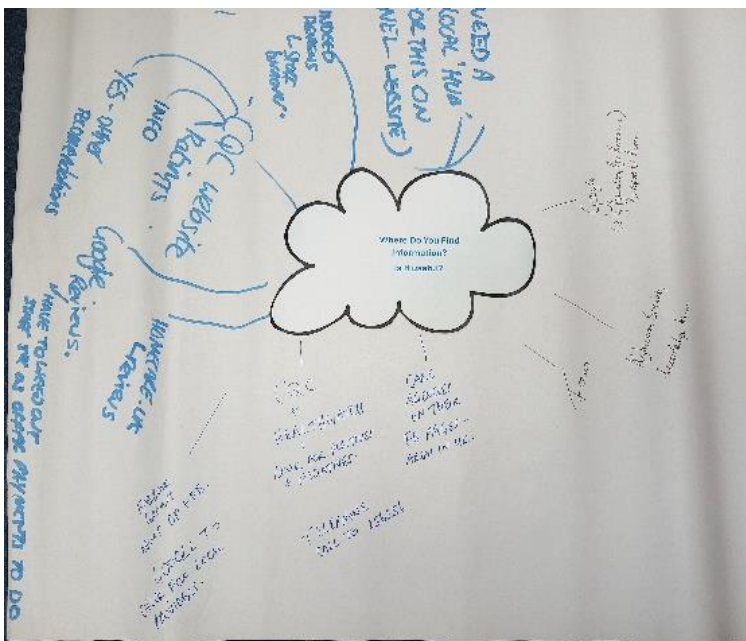


## Positives

### How do you get information?

Informal Carers said that sometimes it is not easy to find information and you must go to several places. Informal Carers said they have learnt to do their own research on services, and they use several mechanisms, these include:

- CQC
- Healthwatch website
- Google
- Care Agencies – websites & social media.
- Google reviews – **“you have to weed out some staff comments as they are often given incentives to post reviews”.**
- ASC.

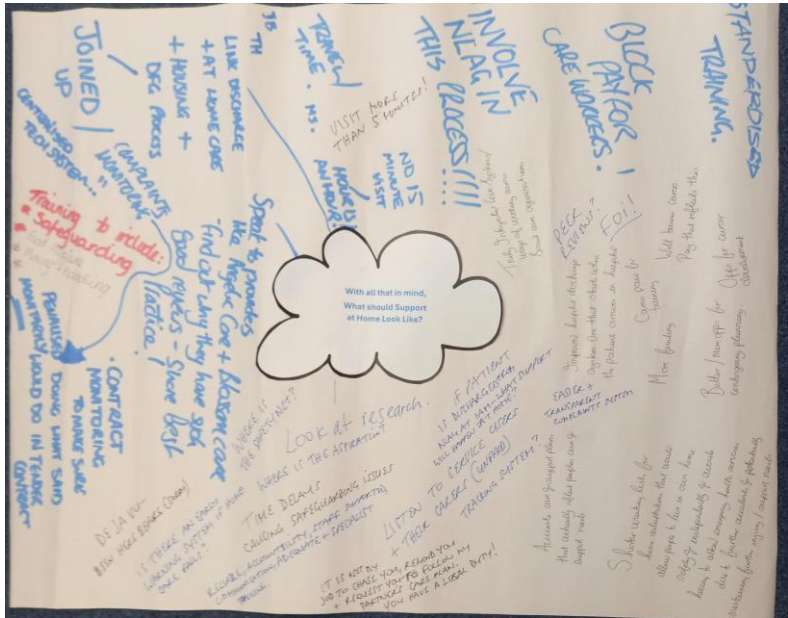


### How Do You Find Information?

### Is it Useful?

They find it useful when they have managed to find what they are looking for, also that it can be time consuming as it is difficult sometime to know exactly what you are looking for. The group felt that there had to be a quicker way and a one stop shop where it would all be in one place.

### Future Design of Service and What It Should Include



The group discussed what they would like support at home to look like in the future and have recommended the following:

#### Training for Care Staff

The group suggested that there should be mandatory training for all care staff. This was to ensure quality assurance across North East Lincolnshire and it was recommended that the Quest system is used so training records can follow carers so if they do change jobs, they do not constantly have to renew their training. Also, informal carers would be confident that all carers have been trained to the same standards. This training would include:

#### Mandatory for all carers

- Safeguarding
- Health & Safety
- Moving & Handling
- Manual handling
- Food hygiene
- Nutrition & Hydration
- Medication
- CPR

For those people with more complex needs the training would be offered to staff to ensure they have the skills to care for them appropriately. This may include peg feeding, stoma care and anything identified as a speciality need.

Care Agencies should have members of their team that are trained, in reserve, so if a carer is off sick or there is an emergency then care can be covered, instead of assuming that the informal carer will step in and cover for the Care Agency.

Care Agencies have in-house training, but informal carers are unsure of the quality of this as it can often vary from agency to agency.

**The group suggested that if all this was in place, then we could be assured that all carers are trained to exactly the same standard and this would be 'Good Practice' across North East Lincolnshire.**

### Support to Providers

The group felt that to achieve a good standard of 'Best Practice' worked needs to be carried out with providers and find out why some services good reviews and share learning across support at home services. As part of this to look at research and to work out where North East Lincolnshire's aspiration is and what do we want providers to achieve and how can we support them to achieve this. Contract monitoring to be robust and to ensure providers are doing what they said they would do. This would support providers to again, strive for 'Best Practice'.

**The group suggested that if all this was in place, then we could be assured that all our support at home providers are supported to achieve best practice across North East Lincolnshire and if there are issues they are raised early enough for a contingency plan to put in place so those that receive services are not impacted upon.**

### Information Hub

A central system needs to be set up so you would have a 'one stop shop'. It would contain information and community This would mean you can go to one place and find out what Support at Home means, how you can get support and who to call if you need help.

**The group suggested that there needs to be an information 'Hub' for Support at Home on the NELC website. This would enable those that use Care at Home and their informal carers to access information and useful contact numbers from one place.**



## Complaints Procedures

The group felt a clear and transparent process was needed for complaints to ensure all complaints or concerns raised about a care provider are dealt with independently and not just by the provider. This will ensure that concerns and complaints are dealt with in a fair and unbiased way.

**The group suggested that there be an independent organisation to deal with concerns and complaints**

## Response From North East Lincolnshire Council

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“We welcome the report carried out by Healthwatch on support at home services in North East Lincolnshire. We want to thank everyone for their contribution to the report and the time people have taken to feedback their views. This report will play a pivotal role in the shaping of support at home services in the future as we develop the specification for the new contract. We want to use this report as the basis for further partnership and co-production with people with lived experience in the design, development and evaluation of support at home services.”

Katie Brown – Director of Adult Social Care.

## Acknowledgements

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We would like to thank all those that have shared their views with us. We would also thank those agencies that have supported us.

## References

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<https://careplusgroup.org/the-curzon-centre/> (January 2024)

Care Act 2014 - <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm>

<https://www.friendshipathome.org.uk/>