

Support and help for people who care for others in West Essex

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1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience.

One of the functions of a local Healthwatch under the Health and Social Care Act 2012, is the provision of an advice and information service to the public about accessing, understanding, and navigating health and social care services and their choices in relation to aspects of those services.

The Healthwatch Essex Information and Guidance team are dedicated to capturing the health and social care experiences that people in Essex are encountering daily. The team respond to enquiries relating to health and social care and are equipped through training, to offer specific information to the public or other professionals. The team are well placed to listen, reflect on and support people to share difficult experiences such as the one's shared in this report.

1.2 Topic Background

In 2021, Carers UK estimated there were over 13million people caring for a disabled, older or seriously ill relative or friend across the country.

In many, many cases, this means juggling work and other commitments while care giving or caring full time on a carers allowance of £69.70 (2022/23).

These 'unpaid' carers are estimated to save the government a staggering £135bn per annum.

However, we know that many do not consider themselves 'carers' and are not registered as such - thus the estimates above.

As our population ages and life expectancy with a long-term illness increases, more and more people are taking on caring roles.

The cost of private healthcare makes that option restricted for many, and the reputation of the care sector pushes many more into caring for their loved ones themselves.

New unpaid carers are often completely untrained, and unprepared for what they are taking on. For them to succeed, and maintain some sort of quality of life, it's important that the support and advice is not only in place, but easily sourced and accessible to all.

1.3 Acknowledgements

Healthwatch Essex would like to thank the members of the public who participated in this project through completing the survey. Our thanks are also made to those individuals who took the time to speak with us and share their personal stories. We would also like to thank our partners, contacts, and networks who helped publicise the survey.

1.4 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement period. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

NHS England has set out the following as the four core purposes of ICSs:

- a) improve outcomes in population health and healthcare
- b) tackle inequalities in outcomes, experience and access
- c) enhance productivity and value for money
- d) help the NHS support broader social and economic development.

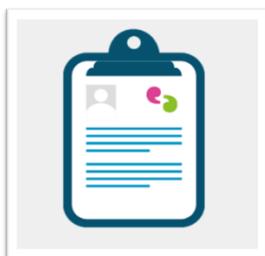
Unpaid carers provide a vital role in population health and healthcare, ensuring the elderly, those with a disability and those with long term conditions get round the clock physical care, emotional support, love and understanding at marginal cost to the NHS and Government.

Taking these roles and ensuring these committed carers have access to the best support, advice, and respite, and ensuring they are listened to, valued and respected, delivers across all four of the core purposes.

Through this report, Healthwatch Essex aims to voice the lived experiences of carers in West Essex, to highlight their support needs, and allow comparison to be made between those needs and what is being delivered through the ICS. This will provide insight into what is going well, what could be improved, where there might be blockages in the system, and what on-going programmes should be in place.

2.1 Engagement methods

Participants were contacted through the Healthwatch Essex website and newsletters, partners, other organisations in West Essex, relevant online communities and through word of mouth. They were engaged in two ways:



Survey

A survey was created to gain perspective and insight from residents who have had experience of caring for family members, loved ones, friends and neighbours.



Interviews

Individual interviews were conducted to collect personal stories from members of the public. Interviews took place by telephone during December 2022 and January 2023, and all participants gave their consent to have their interviews recorded. Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and confidentiality of information they provided, all names used are pseudonyms to protect identities.

2.2 The Survey

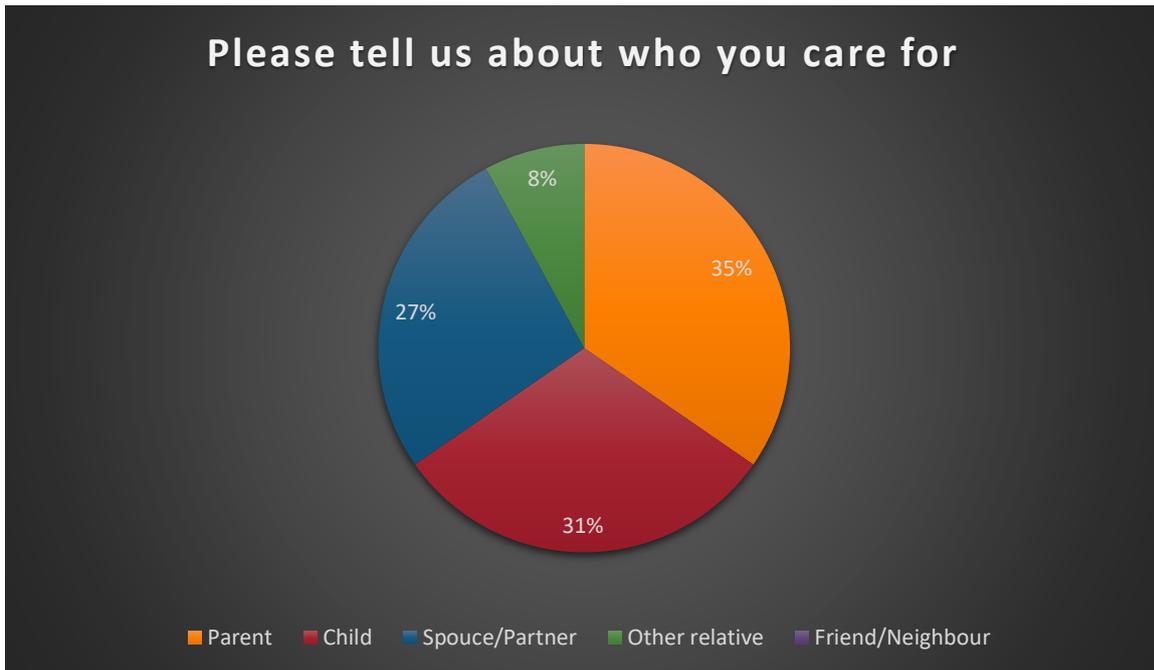
The survey consisted of 13 questions including 3 ‘free text’ answer boxes enabling the participants to give expansive answers sharing their experiences and thoughts.

It was devised to encompass:

- Who they are caring for.
- How many ‘caring hours’ they perform each week.
- Their knowledge of Carers Allowance.
- What support they would like.
- Their relationship with their GP.

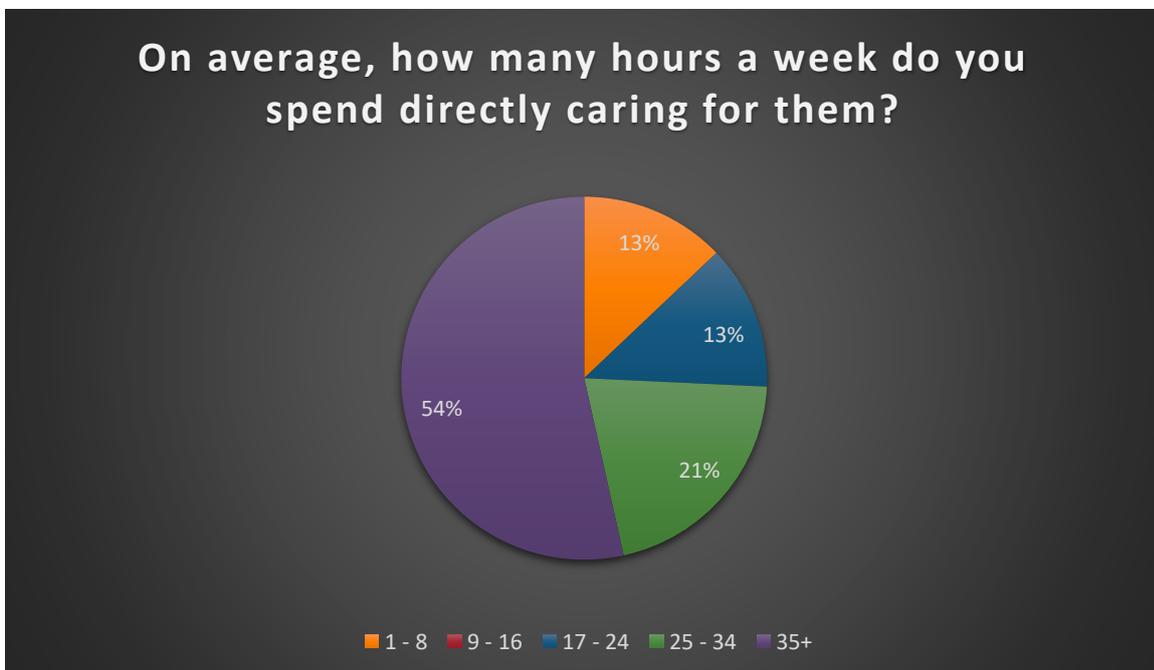
The survey was primarily in an online format but was also available to be printed off and filled out manually as required. The Information and Guidance Team at Healthwatch Essex were also available if the survey needed to be completed in any other format, such as over the telephone. The questions, and responses received, were as follows:

In our first question, we asked about who the respondents are caring for:



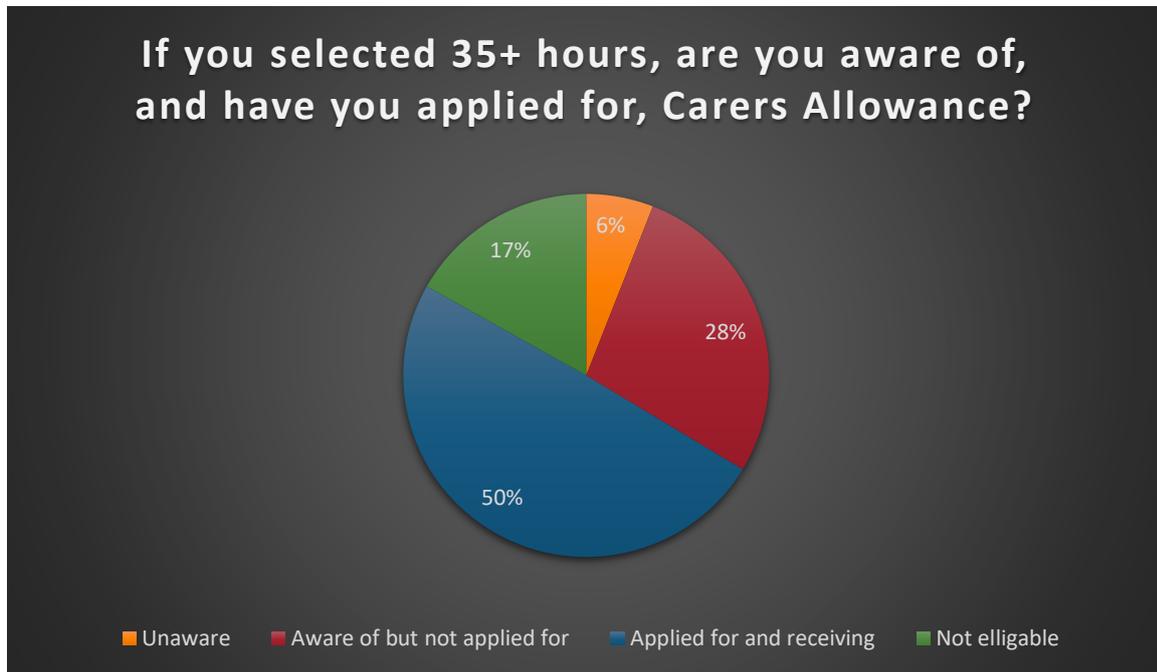
None of our respondents were carers for a friend or neighbour.

The second question asked how many hours they spend caring:



75% of the responses were from people caring for someone for 25 hours or more a week, with 54% caring over 35 hours, and thus potentially eligible for Carers Allowance.

Question 3 asked about their awareness of Carers Allowance:



This shows very positive feedback that only 6 percent of respondents are unaware of Carers Allowance. The area of concern is the 45% who are either not eligible or are aware of it but have not applied. What are the reasons for this, why have they not applied? If you are caring for someone for 5 or more hours a day, surely it is only right that you receive financial help as you are inevitably helping take some strain off health and social care resources.

Question 4 was a free text response:

‘What support could be offered directly to you that would help with your physical and/or emotional wellbeing?’

Here is a representative selection of the answers:

- *Knowing what support is in my area so I can talk to other people in my situation.*
- *Care support much earlier in parent's decline in health.*
- *Respite care.*
- *A welfare check on me, someone to talk to when I can't cope.*
- *Get help from the social workers - they are disgraceful and never call.*

- *Receiving support by social care to find appropriate support and access to specialist healthcare.*
- *Support group, access to information and advice.*
- *Someone else to do the 24/7 role that has been foisted on me so that I can have a life.*
- *Respite, safe care for my autistic son and his brother so I can have a date with my husband as we have no childcare other than during school hours when my husband is working.*
- *Respite.*
- *Fund a break from this role for 4 weeks a year which allows my mum to stay in her home with support. This should not affect her or myself financially. Any other job includes paid leave and it's seen as a legal right.*
- *A chance to stop and breathe.*
- *Someone to talk to.*
- *Advice on how to cope with severe dementia.*
- *More flexible medical appointments for myself.*
- *A place to talk and meet others and get expert advice over a coffee.*

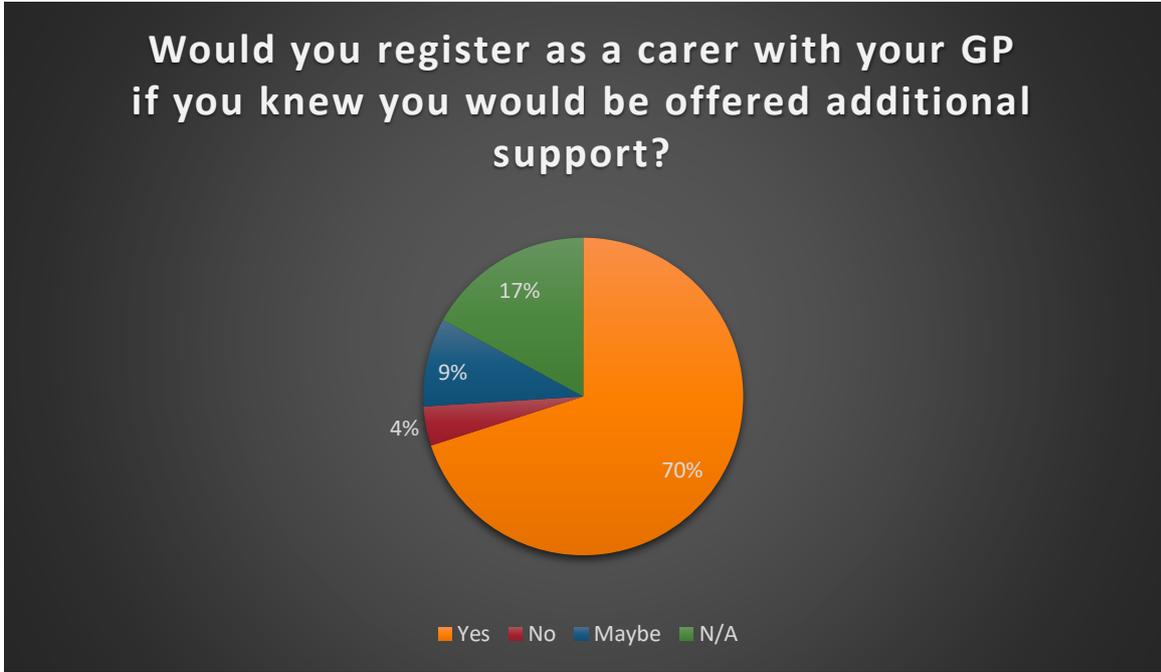
The next five questions all relate to the relationship with their GP.

Question 5:



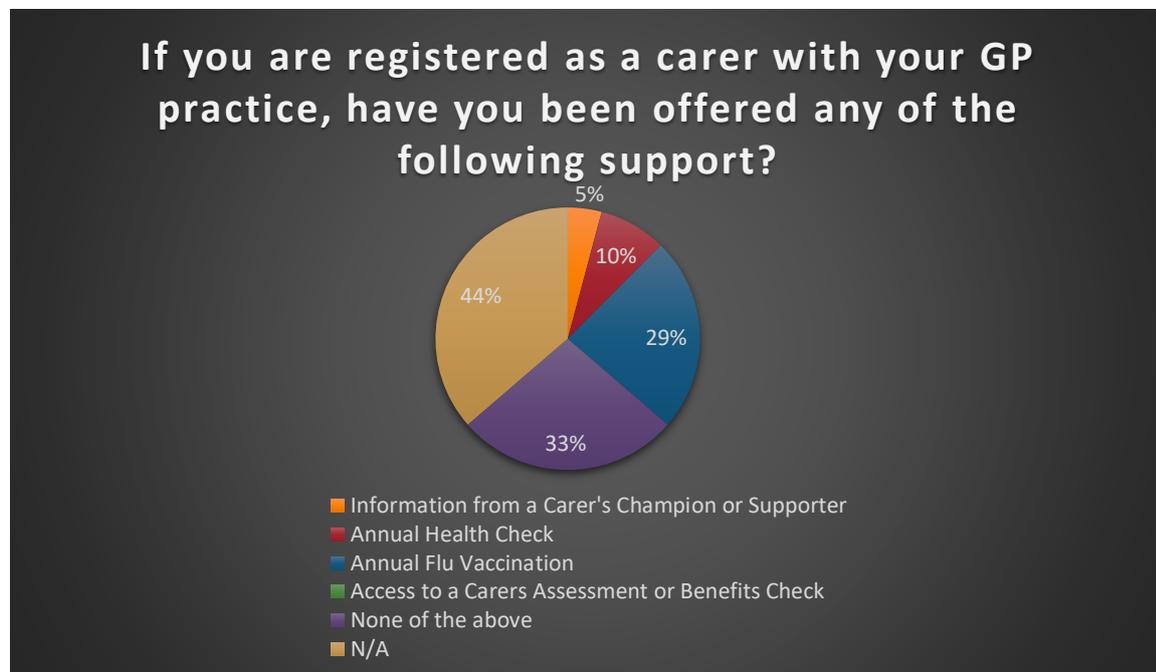
42% not being registered with their GP as a carer is extremely high and highlights a clear breakage in the system.

Question 6



Unsurprisingly, the significant majority would register with GPs if they knew there was additional support available.

Question 7 asked about the specific support being offered:



Only 5% were offered support from a Carer’s champion, so unsurprisingly as a consequence, not a single person was offered access to a Carers Assessment or benefits check. Furthermore, 33% selected ‘None of the above’.

Question 8 asked for details about support given by the GP practice.



Unfortunately, no-one described their support as very good. It may be that the 'neither good nor bad', 'bad', and 'very bad' could all be grouped together as a result of GPs just not offering any real type of support and not pro-actively questioning if patients are caring for someone.

Question 9 returns to an open text answer format:

'How do you think GP practices could better support carers?'

Responses included:

- *A separate telephone number so we don't have to sit on the phone for hours only to find all the appointments have gone.*
- *I was unaware of this.*
- *Yes, but they are snowed under.*
- *Phone call to check on us and people we care for flexible appointments around our caring duties.*
- *Just to be bothered about us would help.*
- *unfortunately we are Herts & West Essex health area, I no longer think about it , the system is what it is, and we just adapt to the services available.*
- *Make time.*
- *Awareness of caring responsibility.*
- *They dont support.*
- *More flexibility with appointment times. Giving information for further support/advice.*
- *Being more considerate and making appointment booking in general easier. When working full time and trying to book appointments for the person you are caring for is even harder. Being told to call at 8 in the morning to make yet another appointment is impossible. I run out of days leave as it is to care for my Mum so I can't not go to work on a day in the hope I may get her an appointment. My mother's GP practice are also very unsympathetic to her circumstances and make life very difficult and are often very rude. They are definitely not dementia friendly.*

- *Help and advice would be wonderful, I've had so much difficulty trying to find services, groups and benefits, it's exhausting and very worrying. I want the best for my husband for his remaining years.*
- *Appointments around caring duties, a mental health and welfare check.*
- *Make it easier to get appointment, deal with more than one thing at a time.*
- *Proactively offer me support as well as guidance ref health conditions of those I care for.*
- *Checking in on their mental health.*
- *By showing an interest in the patient. My husband was not contacted or seen for 4 years after his dementia diagnosis.*
- *It is very hard for them due to poor infrastructure and terrible services.*
- *Make appointment booking easier.*
- *Looking out for them more, holding meetings.*
- *Making sure they know about registration with them.*
- *Doing less stuff online would help as my elderly mother isn't great with booking things online. She's much better just doing it the old way of telephoning and making appointments. She likes to do these sorts of things but more and more things are moving to online and automated which make her a bit nervous.*
- *The majority of appointments were held with the GP, but a quarter of them were with a practice nurse.*

Following this, question 10 was a very open question:

'Do you have any other experiences or thoughts you'd like to share?'

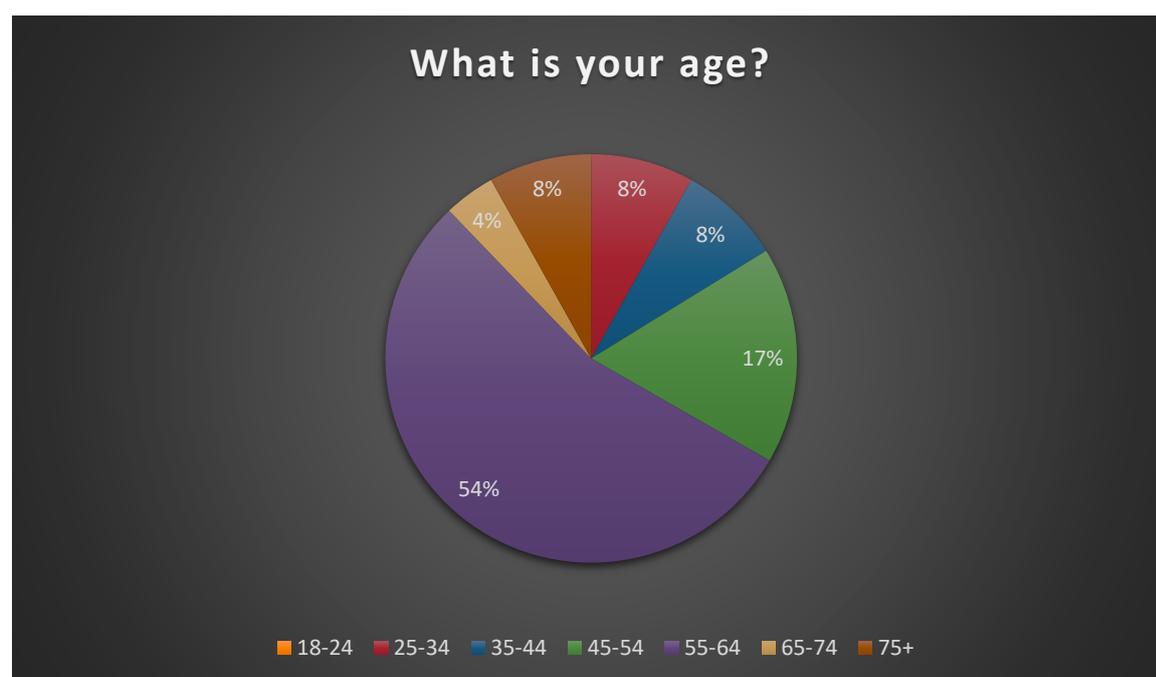
- *My mum died recently, and I was her carer up until she did. It was a long and slow decline meaning this impacted my wellbeing over a period of time. It wasn't until the last 2 weeks of her life that we were offered any type of emotional or physical support (when the hospice was involved).*
- *My daughter has been very ill recently, and we've had very little support and part of the reason she got so bad was we couldn't get a GP appointment.*

- *There is currently limited support for carers. Care assessments for the cared for and care support provided for them, but not carer. Carers assessment is so limited.*
- *I wasn't aware of any support for me as a carer.*
- *Once my daughter became an adult a lot of support for me stopped. GP doesn't care despite my daughter having been very ill for over a year no one bothered to see how I was coping mentally, physically or financially.*
- *I have a lot of problems getting my prescriptions.*
- *My husband was diagnosed (dementia and sight loss). We were given ZERO info and support by anyone. I have had to research and fight every inch of the way to get what we are entitled to.*
- *Dunmow in particular is very poorly served and has poor MH/LD healthcare and no integrated services for adults.*
- *I feel totally overwhelmed at times and underappreciated, nobody cares.*

Demographic Questions:

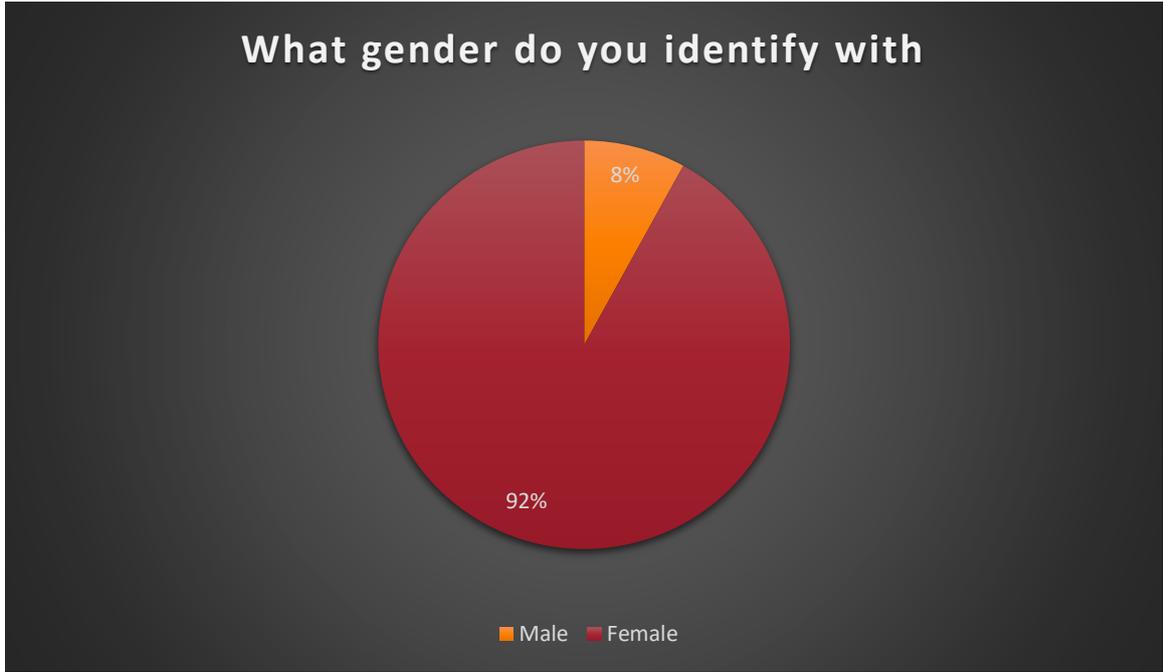
The next section of the survey asked for details of the individual respondent.

Question 11



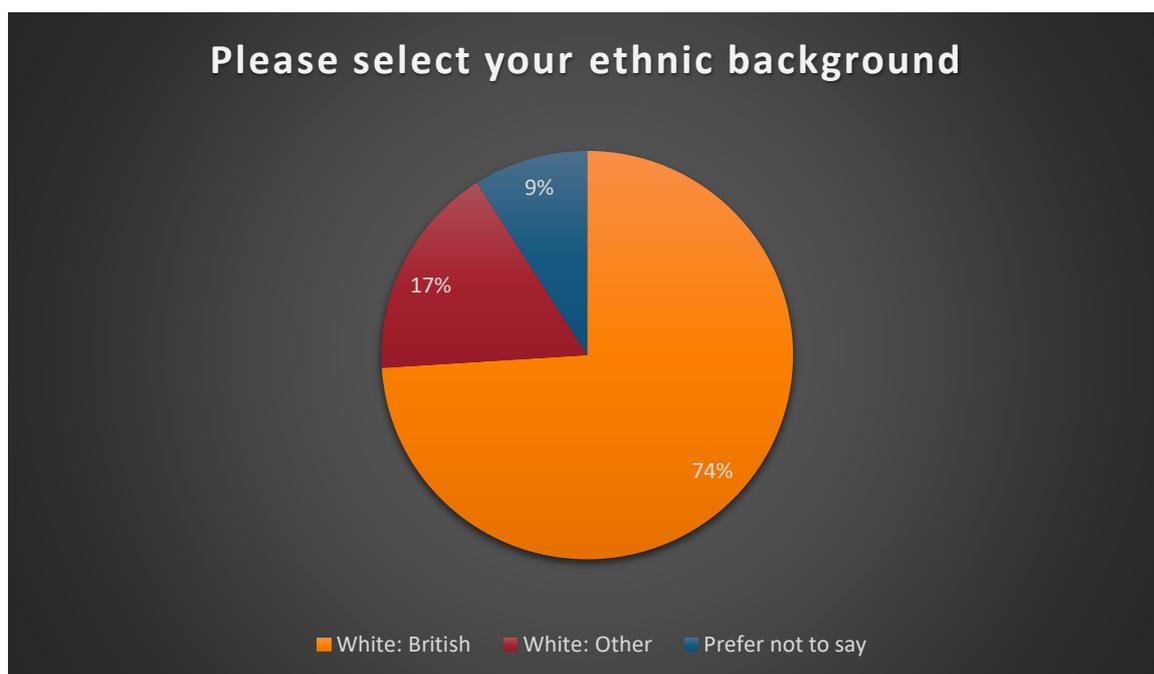
Nobody under the age of 25 completed the survey, while over half of the respondents were aged 55-64.

Question 12



Other options were available, but all our respondents identified as Male or Female.

Question 13



All options were available, but respondents selected only these three choices.

2.3 Interviews

Many people offered to talk to us directly and tell us about their stories in depth. We would like to thank everyone who took the time to talk to us and share their experiences. We have highlighted some of these lived experiences below with names changed to protect identities.

Case Study 1

Alison

‘I think of myself as a dogsbody, not listened to and constantly ignored.’

Alison has been a carer for her daughter since she was born 31 years ago.

‘I worked initially, but the demands became too much to cope with and I had to stop.’

In more recent years, Alison has also taken on caring for her mother who has developed dementia.

‘With my mother, there has been a certain amount of understanding from the GP, but they wouldn’t refer her to a Dementia team, saying they would deal with her directly.’

After time her mum went into a care home, but when she had to go to hospital, she struggled to get any information:

‘I was kept completely out of the loop.’

During the whole of the period since her mum’s dementia diagnosis, Alison felt let down by the system that should have been in place:

‘I got no advice, no help from Social Care, no help regarding finances, benefits or choices.’
‘Eventually I got our MP involved and that finally seemed to get some results, although the social worker was pretty rude and dismissive of the MP, saying ‘you don’t think we listen to what they say do you.’’

The lack of care and understanding for her daughter is very upsetting for Alison:

‘Nobody wants to stand up and take responsibility, everyone wants to pass her on to somebody else.’

‘It’s always been me pursuing all different angles on her health so she can be supported.’

‘Her social worker doesn’t understand her needs, social care are ignoring her continually and it all comes back to me.’

Alison had breast cancer recently and wanted to organise support for her daughter while she was in hospital.

‘I was told I would get a support plan, various types of help etc, but the social worker then seemed dismissive, and we never received a support plan.’

‘She was left out to dry.’

Alison gets no respite.

‘I get depressed about the future in every respect. I have no quality of life.’

She needs her daughter to be helped - that’s the one thing that in turn will help her.

‘My daughter needs a good social worker, alongside appropriate and responsive healthcare.’

‘The GP surgery is good, but they acknowledge that they know little about what to do. They asked me to research what they can do, to do the fact-finding!’

Alison’s thoughts about being a carer are not uncommon:

‘I don’t want to be a carer, so I’m resisting applying for a carers allowance as I think that will be the final nail in the coffin.’

She constantly worries about the future and is desperate to get things in place for when she dies.

‘I don’t know how my daughter will be able to cope emotionally when I die, especially if a whole load of new people come in and take over.’

‘I’m worried she will be overlooked, and her vulnerability will result in her getting into dangerous situations and getting taken advantage of.’

Very reluctantly and guiltily, Alison admits that sometimes when her daughter’s mental health dips, she almost hopes she has to go into full time care, which would possibly be an institution.

Case Study 2

Julie

‘My mum was in and out of Princess Alexandra Hospital three or four times in one year. She had complications with her cancer treatment and on the last occasion was in for six weeks.’

‘When she was discharged after her last visit, no support was put in place or even discussed.’

‘When I asked why there was no support, I was told ‘because she has family’. That was despite the fact that she couldn’t walk on her own.’

Julie’s dad worked and was initially her main carer. Julie worked full time and supported him as best she could.

After time, her Dad cut his work hours by half, Julie did the same and they did shared caring.

There was no care package in place:

‘We were told she would be referred for help, but nothing happened and no-one came.’

Julie was worried for her Dad, not herself:

‘He got no support, was never asked by anyone.’

‘Dad was offered nothing, no advice or help or signposting anywhere.’

Towards the end before her mum went into the hospice, the district nurses paid a visit:

‘They said they would come again if she needed help, but every time we called them, we got no answer and they never came again.’

When she took her mum to GP appointments they were great, but they never offered to help with support or signposting or any ongoing advice.

‘At one point I was trying to find a nutritionist, but they didn’t help at all.’

‘If the person you are caring for gets the right care, it helps hugely with your own mental health. That’s what I wanted in place.’

Case Study 3

Fiona

Fiona cares for her husband who has cognitive impairment / vascular dementia and macular degeneration. She also cares for her mum who is elderly and needs general care.

She had to take early retirement from a long and successful career. Her pension now pays for all her husband’s care.

She wants him to live at home for as long as possible and do what they can together.

‘I use a tracker to make sure I know if he wanders off while I pop out.’

‘I get no other regular care help as you have to pay for it. I’d rather spend the money on doing stuff with him while possible.’

‘Respite would be great, but even a sitting service costs a lot of money and all they do is sit there and don’t do anything.’

Dementia Adventure and Alzheimer’s Society have been helpful, but it’s Carers First who have been wonderful, according to Fiona.

However, she points out:

‘Nobody told me about Carers First, we just got lucky hearing about them.’

‘It’s taken 2 years to find everything we currently access, but I got no help from anyone.’

‘I’m registered as a carer with my GP, but I get nothing. I’ve not had a single conversation with them about help.’

‘I found out about social prescribers from another person, but the GP surgery had never mentioned it!’

‘As soon as we got the diagnosis, I should have been given a list of people and places to register, visit, join etc.’

‘A social worker did his needs assessment and put some things in place. The NHS did the carers assessment, but why don’t they use that opportunity to put a plan in place for my needs as a carer? I didn’t qualify for the money and never heard anything from them again.’

Fiona feels incredible stress and strain from having to attend different consultants in different hospital, travelling around and having to constantly push for results, follow up, and treatment.

She is constantly frustrated by trying to navigate a system that is rigid and inflexible and lacking in any common sense:

‘Once, the GP told me he needed another appointment in 2 weeks. I went to reception but was told the only way I could make an appointment was on the phone. So I stepped outside, called the surgery, spoke to the same woman I’d just been speaking to on reception and made the appointment for 2 weeks’ time.’

Case Study 4

Jackie

After persuading her mum to move to Harlow to be nearer her, Jackie stopped working and became her full time carer.

She was increasingly worried that her mum was less able to look after herself, and was very relieved to have her living close by.

‘I get tax or national insurance credits to ensure Mum keeps her benefits as I was told she would lose them if I got Carers Allowance.’

‘Mum has multiple health problems and mobility issues, but is in a bungalow now and gets around with walking aids and so on.’

‘Adult Social Care came and assessed her and helped a lot, including helping organising for a carer to help her shower, which is so important for her dignity. They also pointed me towards carers organisations, groups and Facebook pages which have been really useful.’

Jackie does her washing and cleaning etc, and also has power of attorney which helps when doing various bits of paperwork and finances.

‘I use her account on the NHS app on my phone which is great for keeping up with letters, follow-ups, and things like that.’

They joined a group in Harlow who meet at the Latton Bush centre in Harlow and go along when they can.

The Carers group organised some respite so she and her husband could have a couple of nights away:

‘Respite care is so valuable, it makes such a big difference’

She is also happy with the response from her GP:

‘I am registered as a carer and have had my health check and flu jab. They have a carer specialist who has been very helpful and supportive.’

‘The GP is on the ball regarding my mum and liaises very well with me.’

To improve things, she would like a support group for herself with people of a similar age in a similar situation, but finding one has proved difficult.

She would also like to leave her Mum at a group meeting:

‘It would benefit both of us a lot, but I’m not allowed to because she’s in a wheelchair.’

Apart from the one break she had, respite is very rare, and she admitted that it ‘puts additional strain on my relationship with my husband.’

3.0 Key Findings and Recommendations

There are a number of easily identifiable tools and structures that can be implemented to offer the help and support that can make a significant impact in the health and wellbeing of carers and those they care for.

Much of the support is there - the positive comments in this report reflect that.

Many of the issues that need addressing are centred around disseminating the information and enabling access to these services.

Too many carers feel ignored and lost, they need to be recognised and have pro-active support and guidance from professionals who show they care and understand.

- Care for the cared-for person

First and foremost, we must not lose sight that the best thing that can be done for carers is to ensure the person they care for is getting the level and quality of care they need and deserve.

Listening to and understanding their needs respectfully and with compassion and working hard to find the best possible solutions.

Taking responsibility, not passing them on.

There is little point investing significant time, resource and effort into other fields if this core principle is not working fairly and efficiently across the board.

- Respite

Caring is draining and exhausting, both physically and mentally. Carers give up a 'normal' life and often take a big financial hit to do something they simply have to. While they are happy to do it, the fact is that they feel duty bound to do it.

It can be relentless, and it impacts everything.

Even the shortest bit of respite can make a huge difference. However, often (but certainly not always) the carers who most need the respite are the ones who care for people with the most complex needs, so specialist carers are needed to cover.

This is an area that needs careful and thorough consideration. Whether it's being able to leave a person in a wheelchair at a support group for 2 hours, or finding appropriate care overnight for someone with specific medication requirements while their carer can stay a night away, all factors and variables need to be provided for wherever possible.

- The role of the GP Surgery

Pivot point

The GP surgery remains the cornerstone of the health service. The shop window, the consistent and reassuring presence, the first port of call when you're unwell.

They are busy, they are pressurised, but they are uniquely placed to be the pivot point between carers, the people they care for, social workers, support groups, charities and others.

GP's must start by questioning and registering people as carers. They then schedule relevant health checks, and vaccinations. There should also be consideration to developing some flexibility in their systems for appointment booking.

Pro-active dissemination of information and resources

Carer leads within GP surgeries, linked in with social prescribers / care advisors / Community Agents etc. don't need to know everything, but it is they who can click the system into gear and give appropriate initial signposting and support. The tentacles then continue to reach out to source the specific help that will provide the greatest benefit.

- Key areas to always cover

Respite (e.g., Carers First)

Local support groups (e.g., Essex Map)

Emotional Support (e.g., Essex Wellbeing Service)

Financial help (e.g., Citizens Advice)

Social Care (Essex County Council)

- Hospitals and other healthcare settings

When people are diagnosed, when they are discharged, when they are seen by a mental health unit, when they are seen at a falls clinic, wherever it might be, it provides an opportunity to question them and their carer about the wider support they are getting. Physical health, mental health, wellbeing, isolation, living conditions and many other factors.

A simple recommendation (or direct referral) to a GP Carer Lead, or even some key relevant fliers (Alzheimer's Society, Essex County Council Adult Social Care, Essex Wellbeing Service, Mind, etc).

Being pro-active in approach remains key. Staff could give them a 'Please register me as a carer' card to hand to their GP, and fliers must be handed directly to them, not just placed in racks where they are easily missed.

4.0 Conclusion

By listening to the lived experience of carers and their family, it is hoped that the findings in the report will help the HWE ICB to identify areas of structural change, alongside key services to develop and commission to match and reflect the increasing numbers of unpaid carers and their core needs.

The services come from across the board, including the NHS, Local Authority, Community Voluntary Groups, CICs and Charities.

Adapting and moving forwards

Much of the support and understanding that carers want, exists.

There are so many organisations doing so much good work, developing new and innovative programmes, and between them trying to provide something for everyone.

The ‘explosion’ in the number of carers means that the ‘institutional’ structure to support them needs to be updated, streamlined, and simplified.

Focusing on a pro-active approach where people are clearly recognised as having a caring role, and ensuring they have a sense of support and a clearly signposted pathway, laid out to find the services and communities they need.

Carers care deeply and often unconditionally for the people they care for. The emotions they invest are huge, and they can often live on a knife edge, close to despair. It’s only right that they are recognised, respected, and helped to continue doing the amazing work they do.

It cannot be over-estimated and must not be overlooked.

5.0 Terminology and Acronyms

CIC - Community Interest Company

ECC - Essex County Council

GP - General Practice or General Practitioner

HWE - Hertfordshire and West Essex

ICB - Integrated Care Board

ICS - Integrated Care System

PAH - Princess Alexandra Hospital, Harlow

Respite - Taking a break from caring while the person you care for is looked after by someone else.