



Carers Voices

End of year evaluation, 2024

healthwatch

History of Carers Voices

- Project started in January 2024
- Commissioned by Essex County Council to deliver the Carers Voices Project.
- Identify and link with unpaid carers in Essex, empower them to have their voices heard, and influence change and improve access to support and resources.
- To raise awareness of carers rights. Many 'carers' simply don't identify themselves as carers and are not aware that they qualify for help and support.
- We have held several events throughout the initial year to engage with as many diverse groups/areas as possible e.g. focus groups, workshops and surveys.

Meet the team

Carers Voices Officers




Jane Stokes




Tim Beighton



Mel Archer



“Thanks to the Carers Voices team for making a difference in my life. It’s so hard to navigate the services out there, but Healthwatch Essex were there to help.”



Outcomes

- Throughout the year we have targeted areas across the county identifying and engaging with carers across all communities, all ages, gender and ethnic minorities i.e., Chinese, Nepalese, Bangladeshi, Indian, Ghanaian, African, refugees.
- We focussed our efforts on talking but mainly listening and hearing carers tell us about their lived experiences, both positive and negative and building up a picture of services, what they offer and where and the difficulties and barriers carers have accessing timely and appropriate support.
- We have facilitated very useful focus groups across the county. Collating feedback and being the conduit to ECC/EWS. We have gained a good understanding of issues carers face.
- We surveyed carers over a broad range of subjects that directly impact on carers. Topics including communication; loss of identity; young carers; isolation and loneliness (on behalf of ECC).

Impact

Case study: Young Carers needing support looking after parents

- Background: the young carers 11 & 12 have been caring for their parents since the age of 4 & 5.
- Issue: Mum is deaf & mute communicating through sign language in Hindi, which one son & dad can understand. Dad has several health issues and is also deaf & mute and communicates through BLS and can read. Mum feels more isolated as she is unable to understand BSL.
- The boys provide phenomenal daily support, accompanying to shopping trips and appointments, translating school letters & emails in BSL for their father who then translates in Hindi to his wife. Advocating on their parent's behalf, answering mobile phones and reading the mail. The parents struggle when the boys are at school.
- The boys receive support from RAMA and the parents from The Sound & Vision Sensory Team but have expressed help with schoolwork/homework would be useful and having young people their own age to talk to.
- Referrals made to EWS & A.F.F.C. for YC weekly group support.

Impact

Case study: Veterans - Advice and Guidance to find respite

- **Background** – A veteran who cares for his wife (veteran also) was having difficulty accessing services to find some respite following a difficult period of diagnosis, treatment and recovery, house move and bereavement. They were so engulfed they couldn't find support.
- **Issue** – This couple were having a difficult time following diagnosis of debilitating condition. They were also moving to more appropriate accommodation and coping with bereavement of a family member.
- **Action** – Discussed options and sign posted direct noting the urgency. Couple engaged and were assessed timely.
- **Outcome** – Both were offered respite which was utilised and included the wider family. This timely intervention helped to remove the pressure they were feeling and gave them breathing space to recuperate over a few weeks and are still engaged to ensure no relapse.

Impact

Case study: Developing ways to interact with carers to maximise their experience

- **Background** – We met an older lady called Susan at a forum. It was the first time she had found time to have a break from caring and needed advice and guidance. It soon became clear she was becoming overwhelmed by seasoned carers and professionals with lanyards and name badges.
- **Issue** - Some carers are very stoic and self-sufficient and do not feel comfortable speaking about their experiences when confronted by professionals and carers. It can be daunting, and we wanted to create an environment where all carers feel comfortable and confident to speak to us.
- **Action** – We changed our approach, reduced the use of name badges and structured the sessions and interactions to be more inclusive. We called this developed approach ‘Susan’s Law’. and immediately got much improved feedback.
- **Outcome** – Better, more informative, much more inclusive feedback.

Impact

Case study: Social isolation and lack of support available

- **Background** – Adult carer has been caring for her mum for 15 years.
- **Issue** - Mum contracted Meningococcal Septicaemia, left partially sighted, wheelchair bound and completely reliant on others. Post amputation prognosis for life expectancy was 3-5yrs max due to the extreme shock to her body.
- **Action** - The challenging aspect of becoming a full-time carer was X's disconnection from all her friends who lived the lifestyle that she could no longer enjoy or participate in. There was a significant negative impact to both X's physical and mental health in addition to a cervical cancer diagnosis requiring chemo and radiotherapy treatment. Limited support from Social Services regarding support to source respite for mum or sharing knowledge of financial support available, i.e. Personal Independent Payments etc.
- **Outcome**- the carer shared from her experience that a carers anonymous group setting would be beneficial to talk openly & honestly about their experiences & physical resources, i.e. wheelchair accessible places.



We've engaged with **2,715** carers
as of 30th November 2024.

**“Sometimes the carer requires more support
than the cared for person. Thank you for
asking how I am.”**

**“Had Healthwatch not spoke to me, I'd never have
known what was available to me in my local area.”**

“Thank you for supporting me.”



Future plans

Engagement for 2025

- Utilise our knowledge and experience of carers to build on the successes of 2024 deep into 2025.
- Engage with more ethnic minority groups, hard to reach communities and young carers.
- Utilise the purpose built Healthwatch Essex Community Van to travel far and wide to more remote areas and access more carers. **We'll go to them!**
- Continue to raise awareness and engage with service providers in receipt of Carers Community Funding so carers can access local, easily reached and much needed support.
- Where appropriate, refer carers to EWS in a timely and effective way so they can get support.
- Help carers and remind them constantly of the vital role they play in the carer system and how it is appreciated across the health and social care spectrum.

Greatest achievements

- We have built up detailed picture of services, blind spots for support and are able to link carers to the most appropriate support quickly.
- Our work over the last year has been targeted and wide ranging , we understand the issues and barriers carers experience when trying to access support.
- Referred carers quickly to organisations and services that have made an immediate difference to carers and the cared for and saved them time, energy and precious resources.
- During outreach on the high street, and speaking to carers, we collaborated with our Comms team and created this purpose made song to promote Carers Voices. Our song was well received by the public. Please click on the audio clip, seen right.





Using our purpose
designed vehicle
to access hard to
reach communities



“At times it was really hard (being a carer) and other times were moments of pure joy.”

“I’m aware there isn’t a manual for caring because everyone’s situation is so different.”





“Carers aren’t seen as an individual, you are seen as that person’s carer, so that person is an individual, but you are the carer, not a person, a carer. And when it comes to your benefits or what you may be entitled to, again, you’re not an individual because your partner owns too much or the (cared for) person owns their own property.”

“Dealing with Social Services was an absolute nightmare.”





Total number of carers engaged with **2,982**

Age group breakdown:

Under 25yrs **39%**

Over 25yrs **61%**

Gender identity breakdown:

Female **61%**

Male **19%**

Prefer not to say **20%**





Ethnicity breakdown:

White	64%
Asian	19%
Mixed and other ethnic group	15%

Disability

Physical	36%
Mental health	7%
Neurodiverse	28%
None	39%





Carer type

Young carer	7%
Young adult carer	8%
Family carer	26%
Adult caring for adult	59%






Carers identified themes

Mental Health – the negative impact for both the carer and cared for.

- Lack of support for the carer when the cared for has a range of mental health disorders.

Carers Rights – there is a lack of awareness due to a number of barriers, information barriers; insufficient communication; complexity of systems; cultural or personal barriers.





Carers identified themes continued

Inconsistent GP services across Essex – highlighting the inconsistencies in support, for example:

- Opening hours - differences in extended hours or weekend services, which may not accommodate carers' schedules.
- Lack of awareness of carers' needs and pressures, ie., the emotional and physical toll of being a carer.
- Frequent GP changes resulting in carers repeatedly explaining their situations.
- Lack of recognition – not recognising individuals as carers or involving them in decision making about the cared for person's health.



Summary

Total number of carers engaged with is **2,715**, as of 30 November 2024

- Carers have told us that if they are given the resources, advice and guidance and access to local and appropriate services early in their caring journey the less likely they are to need more support in the longer term.
- Many carers say they are keen to learn from the outset about caring but are faced with a lack of anticipation, knowledge of the cohort and an understanding of the unique circumstances carers face by untrained and unaware services.
- Our survey respondents were from across the length and breadth of Essex and indicated that Isolation and loneliness is not confined to the elderly, less mobile and geographically or digitally isolated. Isolation and loneliness can impact on everyone.
- The issues, barriers and concerns for carers were common themes, and something easily anticipated at the point of contact. Services need to be joined up and communicate with each other.

For more information

Healthwatch Essex

www.healthwatchesessex.org.uk

t: 0300 500 1895

e: enquiries@healthwatchesessex.org.uk



healthwatch