



Meeting: Southport & Formby Community Champion Network Meeting
10am on 23rd January 2025 held on zoom

Themes: A spotlight on Breathe Easy and Alzheimer's Society

Chair

Linda Wright (LW)

Locality Representative for Ainsdale and
Birkdale

Attendees

Jack Morgan (JM)

Healthwatch Sefton Engagement & Participation
Officer

Clare Blasbery (CB)

Healthwatch Sefton Digital Communications
Officer

Anne Major (AM)

Locality Representative for Southport Central

Julia Fahey (JF)

Southport Macmillan Centre

Caroline Louise Hall
(CLH)

Alzheimer's Society

Rosie Norman (RN)

Alzheimer's Society

Caroline Hesketh (CH)

Sefton Carer's Centre

Jan Comer (JC)

People First Merseyside

Lesley Curran (LC)

People First Merseyside

Simon Walker (SW)

People First Merseyside

Hannah Smart (HS)

People First Merseyside

Guest Speakers

Barry Lyon

Alzheimer's Society

Simon Barson

Breathe Easy

Apologies received

Amanda Williams

Healthwatch Sefton Signposting
and Information Officer

Ken Lowe

Ainsdale Medical Centre PPG

Kate Pope

Salvation Army

1. Introductions and Housekeeping

LW welcomed all members to the January meeting, thanked them for their attendance and notified attendees that the meeting was being recorded. LW also noted that she wished to give credit, thanks and respect to retiring chair Brian Clark (BC). LW gave attendees some information about herself, such as her background as a Speech and Language Therapist and her managerial position in the NHS, explaining

her motivation to be a part of Healthwatch Sefton and ensured attendees knew that these meetings are for them; Healthwatch Sefton are open to suggestions and ideas of what attendees wanted to see. All attendees introduced themselves with their name and organisation and apologies were recorded.

2. Code of Conduct/ Declarations of Interest (in line with agenda items or changes)

LW reminded all members to abide by the 'Kindness and Respect' guidelines and follow the 'Healthwatch Sefton Code of Conduct' policy. No declarations of interest were made.

3. Community Champion Network notes for approval

No amendments required.

4. Spotlight on: Alzheimer's Society

BL began by giving a brief overview of what Alzheimer's Society offer to their service users, which is fundamentally the Dementia Advisor Service. This service was developed in line with what people with dementia want, as are all of their services. It is a focal point that service users can use to speak to and explain what happens when someone is diagnosed with dementia. When you get diagnosed, a lot of people can descend on you and it can be very confusing. The service tells people what dementia is, what it means for the diagnosed, what it means to be a carer etc.

BL noted that in Sefton there are a broad church of referrers, and the Alzheimer's Society like to have someone referred as soon as possible when they are diagnosed, but BL made clear that their service is open to anyone that is experiencing the difficulties dementia poses, at any stage of their journey.

The biggest referrers for Alzheimer's Society in Sefton are their memory clinics, which are based in both the north and the south of Sefton, at

Hartley Hospital in Southport and the South Sefton Neighbourhood Centre in Waterloo.

BL explained that there is no office in Southport which was closed due to COVID-19, but the benefit of that is that the service is agile in terms of their delivery; they are very community based. Once they have received a referral, they are very quick to respond, contacting the referred party and offering the service. Then, they do a person centred assessment (in-person or over the phone depending on the circumstance) finding out what they want to know, prompting them where necessary. After the assessment, Alzheimer's Society set about gathering information and then see how to transmit said information to the person, making sure that they are in the loop, making sure the affected parties understand it etc. BL was clear again that even though they start and finish pieces of work in terms of referrals, they are there to be spoken to throughout people's dementia journeys. This is all part of the job that dementia advisors do, which RN and CLH are.

BL explained that dementia is a condition that changes person to person, it's never the same which is why it has been difficult to get systems in place that deliver what people want and need on a regular basis.

BL directed attendees to Linda Lawson (LL), who is very well versed in clubs, services, activities or anything else like that for Sefton residents with dementia. She also acts as a bit of a triage for the team, as she is able to answer lots of questions before referring into colleagues. LL also helps people with famous dementia dilemmas, giving people information on some things to think about regarding these and aiding them. She also acts as a conduit for people's questions and allows the community at Alzheimer's Society to help with these questions, as those experiencing the condition are best placed to help others with common dilemmas, and LL organises all of this. These are all collated onto a list and this is sent out, and kept in Sefton libraries so people can have a look at these. LL raises sessions around the community, physically and virtually, to raise awareness about dementia; Alzheimer's Society have had a couple of events on Teams too with various special guests.

BL noted that while Alzheimer's Society don't run all dementia support groups in the borough, they do run a few. There are two 'singing for the brain' groups in Southport and Aintree respectively, which are for cognitive stimulation. There are also young onset dementia groups, in

Southport and Maghull. BL explained that people with young onset dementia have a different set of issues. If you are getting diagnosed at 50/55, it takes a long time as dementia is last on the list of conditions that one could have to be crossed off.

BL pointed out that while he, CLH and RN are the front end in Sefton, they are a national charity, who do an awful lot of fundraising for the research on the condition, and they have had a big success recently with the 'National Institute for Clinical Excellence (NICE), passing two autoimmune drugs that fights Alzheimer's off that is effective in the early stages of dementia, and have 5 million pounds of funding from the Postcode Lottery to develop a blood test to search for 'plaques' which help identify the disease (currently the only method for this is a spinal tap) as early as possible.

Q (SB): Do you get referrals from GPs locally?

A (BL): We don't get an awful lot from GPs, the majority of our work comes via our memory clinics, but we get other referrals along the way. I think it's something we are looking in the formation of the new Sefton Dementia Strategy, working more closely with GPs. We do get some referrals, but perhaps not in the numbers that we were thinking about. A lot of GPs will have our referral forms and information, but we get most of our referrals from when people have been diagnosed straight away.

Q (AM): Do you advertise in care homes? I have been involved with your service in the past with a family member and I don't remember seeing anything about all of that in the care home.

A (BL): We don't because there is support that is supposed to be given in care homes. We do get carers coming to us surrounding what is going on in care homes, but we concentrate on looking at people in the community. It is not, however, a shut door policy. We support carers that are worried about the level of care or don't understand what is happening. So, we try to explain as best we can what people's rights are. Care homes are subjective, though, in terms of what people think is good or bad practice and sometimes it takes knowledge of what you need to say and who to say it to in terms of how to make a complaint.

Q (AM): I meant more about information regarding attendance allowances and things like that, the financial aspect of things.

A (BL): Well that's definitely given me something to think about.

Q (HS): Is there a certain age where you would get Alzheimer's?

A (BL): People get dementia in later life, post 65 is when the majority get it but we are seeing a rise in people coming forward earlier, the youngest I have seen is 39 but it is not unusual to see people getting diagnosed in 40s and 50s. Its about society reshaping the way that we view dementia, there are going to be more people in 2030 with dementia than there are now due to an ageing population. We want, in our community, to keep people at home, rather than in care homes and hospitals, and our 10-year plan with the NHS is about prevention. It is becoming more common for under 65s to get diagnosed, but majority of people get it when over 65. This isn't a cut off, but a guideline of likeliness. Of course, you could have other issues that manifest themselves that look like dementia, but aren't. We have worked nationally with GPs and have produced the dementia symptoms checklist.

RN notified the network about the drop-in sessions at the Strand by Me Hub from 10-3 on Mondays for anyone affected by dementia.

Q (LW): Are Alexa's provided to patients or do they have to purchase them themselves?

A (BL): There is a portal on the Sefton Council website called Ask Sarah, if people go to that, it will ask what people's needs are and show them various gadgets that they may need. There are charges for these things but people can weigh up the charges and see what they think. With Alexa's, there will of course be a charge.

Q (LW): It is a very difficult financial climate, are there any services that help alleviate this regarding things like Alexa's?

A (BL): I'm not aware of anything like this.

Q (LW): You mentioned a few groups that are open, are any available for us to come and visit?

A (BL): Absolutely.

Actions:

JM to share dementia symptoms checklist with the network, promote drop-in service at the Strand by Me Hub and arrange a potential visit to Alzheimer's Society.

5. Spotlight on: Breathe Easy

SB greeted the network and notified that he had been running Breathe Easy for Southport and Formby for the last 15 years. It is a group of people with lung disease, which 1/5 of the UK population have in some form. The most common are: asthma, bronchiectasis, pulmonary fibrosis and lung cancer. Everyone at the meeting will know someone with a form of lung disease and these people are often isolated.

SB informed the network that they don't often get GP referrals despite his efforts to spread information about the group. The aim of the group is education; if you have a form of lung disease and get a good education about it, you will lengthen your life. Asthma and Lung UK are the parent group and they lobby MPs, fighting for better services for people with lung disease.

SB notified that the group meets on a monthly basis, and there is always a speaker at these meetings. 30+ people attend the group and they are allowed to cough without feeling judged. Through being involved with the group, SB has had the best treatment he can for his conditions as he had the knowledge where he could push for that treatment, and he encourages members to push GPs for the best treatment possible.

SB informed that the NHS are now treating lung disease at its source in order to keep patients at home instead of in hospital, which is very feasible with the right medication and being looked after properly at home.

The group also has monthly lunch meetings, where they get together as a social group, which is really important. The last lunch they went on, 28 people came, chatting and picking up tips from one another on what to do in certain situations. The speakers at their monthly meeting are always people that can help the group, whether it be about the lung issues or something else.

SB notified that his main desire and issue for the group is to let people know that it exists. They have been going for over a decade and people still say that they have never heard of Breathe Easy. There are 250 groups nationally, not just us in Sefton.

Q (AM): Have you asked GP surgeries to put the service on TV screens?

A (SB): I haven't but this is something I will have a go at as it is important to get our name out there. However, I have felt that Practice Managers have been dismissive when I have gone in and tried to talk to them about Breathe Easy and I can't understand why as voluntary services offer great potential to aid their patients. Doctors don't know about us, specialists in lung disease don't know about us.

BW mentioned the importance of talking to people based on a comment SB made in his presentation regarding his lunch group. This Monday (20/01/25) is known as Brew Monday, where we at Samaritans encourage people in their places of work or wherever they meet to take the time to talk to people. Find time in the office, sit down, have a cup of tea and urge people to find the time to see how people are getting on.

Q (LW): When we came to visit you said that patients used to be provided with a recovery pack is that right?

A (SB): They are called rescue packs and they are well-known to GPs. They are antibiotics and steroids as people with lung conditions get regular chest infections. We all know our own bodies and we know when the coughing is different, meaning a chest infection is starting, and I can use a rescue pack to nip it in the bud before it gets going. If we don't have this, it can end in pneumonia and we need to avoid that. GP surgeries are starting to become reluctant to issue antibiotics as they can be misused, and some of our group have been refused rescue packs, and doctors have said to come to the surgery right away when one starts to get ill or fighting for breath, but these are two very different things. A lady at our group who fights for breath on a daily basis has been refused a rescue pack and told she needs to go to the surgery. Getting an appointment is very difficult, and now this elderly lady is in a position that she doesn't know how to navigate. I understand that it isn't good constantly taking antibiotics, but having a prescription of them to stop or reduce the frequency of chest infections does save lives.

Q (LW): Did you also have a concern with the age criteria regarding the RSV jab?

A (SB): The RSV jab, which stops people getting chest infections in winter months, was given to 75-79 year olds. I'm not 75 yet, so I couldn't get this vaccination. It seems ridiculous to me that people within this range could get it and the rest of us couldn't. My partner has never had any chest complaints and was called in to have this jab; I should be the

one of the two of us to have this job. Asthma and Lung UK say that the NHS did a survey for people in this age range and that is why they got the job. They never surveyed people my age nor people over 79; I am hoping the RSV jab goes out to everybody after the way this winter has been.

Actions

- **SB to share leaflet with JM**
- **Any interested parties from the network to contact JM for SB's information.**
- **JM/LW to pass on info regarding rescue packs to Healthwatch Operations Group.**

6. Healthwatch Sefton Updates

JM explained that he has held numerous introductory meetings and attended various events that have yielded positive results, meeting with Caroline Hesketh at Sefton Carers Centre and having a valuable conversation about how their organisations can interact and benefit from each other's support. Additionally, JM notified that he met with Justine Shenton at Macmillan and plans to hold a listening event there in March with locality representatives LW and AM.

JM explained that he, LW, and AM also attended the Keep Warm, Keep Well event at The Atkinson. This event proved invaluable for collecting GP access surveys, which Healthwatch Cheshire will collate into a report for NHS Cheshire and Merseyside. The report will assess the current state of GP access, identify any improvements, and highlight areas for further development.

JM explained that, almost immediately after the November Community Champions meeting, he, along with LW and AM, attended the Practice Manager's meeting for the borough of Sefton. At this meeting, they presented on Healthwatch's value to GP surgeries, clarifying the organisation's role, its limitations, and its objectives in partnering with surgeries in the future. JM outlined that Healthwatch serves as an ally in gathering patient feedback, acting as an additional valuable channel for surgeries to receive insights. He emphasised that Healthwatch does not seek to judge or instruct but rather to inform and support the identification of areas for improvement in patient experience. As a result of this engagement, several surgeries signed up for email updates

regarding Healthwatch's feedback centre, strengthening connections with practice managers and ensuring that the services provided benefit all parties involved in the process.

JM further reported that he, LW, and AM met with Simon Barson and his Breathe Easy Group earlier in the month. He explained that Breathe Easy supports individuals with various lung diseases by providing a space for them to seek assistance with treatment-related issues, share their experiences, and socialise in a judgment-free environment. At this meeting, the Healthwatch team presented on the organisation's role and the services available to patients. They also collected feedback in multiple formats, including one-on-one discussions, group sharing, and written feedback forms, as well as conducting GP access surveys. JM noted that the insights gathered were invaluable, offering significant perspectives for Healthwatch to consider moving forward.

JM also highlighted his engagement with Cumberland House at their PPG meeting earlier in the month. Similar to the Breathe Easy session, he delivered a presentation on Healthwatch's role and services, despite experiencing technical difficulties with PowerPoint. He explained that this engagement aimed to raise awareness of Healthwatch among patients, reinforcing that it is a service available to those in need. The session resulted in the collection of patient experiences and involved responding to challenging questions from PPG members. Following the meeting, JM sent the affected slides to the Assistant Practice Manager, who expressed interest in sharing them with the wider patient population through Cumberland House's newly launched monthly 'Cumberland Spotlight' initiative. JM noted that this initiative is now live on the Cumberland House website, which is a positive step for Healthwatch's publicity efforts.

JM went on to describe a joint piece of work he has been undertaking with his colleague Wendy regarding the GP surgery in Hightown. He outlined that they have been hosting drop-in sessions for residents at the Alt Centre, with one session running from 12:00-14:00 and another from 17:00-19:00, supported by one of Wendy's Locality Representatives. During these sessions, feedback has been collected through one-on-one discussions, mirroring the approach taken with the Breathe Easy Group. Residents and patients of the surgery have been encouraged to share their experiences, which have been recorded on Healthwatch's feedback forms. JM stated that this information will be logged in the feedback centre and used to compile a report that will be submitted to both the surgery and the Commissioner (NHS Cheshire and Merseyside). A

response from the surgery on Healthwatch's recommendations and findings will then be awaited. Two additional sessions are planned in the coming weeks, after which the report will be swiftly progressed to ensure timely support for residents.

Looking ahead, JM provided an overview of upcoming engagement activities. He reiterated that the team will be attending Macmillan's Coffee and Chat meeting to gather feedback on people's experiences with health services. Additionally, visits are planned to Lakeside Church, which hosts a retirement group, and the British Legion, with the aim of engaging with attendees. JM also intends to attend the Southport Action Group meeting to promote Healthwatch, as well as the Brighter Connections monthly Social Group, using these opportunities to present on Healthwatch's services and collect volunteered feedback. Finally, JM stated that he had offered to all attendees at the Community Champions meeting that he is available to arrange visits to any organisation and expressed hope that some will take up this opportunity.

JM provided an update on ongoing operational planning, explaining that visits to care homes and Southport Hospital will be a key focus moving forward.

JM also reported that an internal panel has been established to ensure that recommendations made to commissioners and providers are effectively followed up and that outcomes can be monitored. He noted that there are still places available for membership on the panel and encouraged anyone interested to contact him directly.

JM stated that work is currently underway on a draft report that will share experiences of dental care and the impact of not being able to access a dentist. This report will be shared with the network once completed.

Additionally, JM explained that two reports are due to be published. One will focus on access to primary care for individuals with a learning disability, while the other will examine issues related to Seaforth Village Surgery in the south of the borough.

JM highlighted that the Health & Social Care consultation on advocacy services is now open for individuals to complete and share their views. The consultation launched on 6th January 2025 and will run for six weeks, aiming to gather feedback on advocacy support. Details of the consultation are available on the Healthwatch website

JM explained that Healthwatch Sefton are looking for a Formby Locality Representative, and encouraged the network to reach out to anyone that they think might be interested in the role and put them in contact with the team.

Finally, after the Prime Minister's address regarding the Southport Tragedy on the morning of the meeting, JM reiterated that Healthwatch Sefton are there to support anyone who is affected in any way that they can; there is a dedicated tab on the website that redirects to the council's website for anyone requiring further support. He also notified the network that Healthwatch Sefton will be represented at the Community Impact and Cohesion group

Actions:

- **JM to send out the advocacy services link in his update to the network.**

7. Emerging Health and Social Care themes

BW spoke regarding the Southport Tragedy and said that Samaritans have had calls regarding this and notified the network that their line is open 24/7. He also shared a guide on what to do when you are worried about somebody.

Actions:

- **JM to share link to BW's guide.**

8. Feedback to be taken forward to the Healthwatch Operations Group.

LW pointed out a few themes that she felt needed to be taken forward: the issue surrounding rescue packs for those with lung conditions; expressing concerns regarding the RSV vaccinations; find out more about Dr Paul Walker's service that has been spoken about; ensuring that information is out there for services like Alzheimer's Society and Breathe Easy.

9. Any Other Business

LW has been in contact with Nikki Williams regarding menopause information sessions; they hope to hold a one-off session for Southport and Formby in February before setting up regular sessions, using health coaching and shared experiences to help people with their menopause and signposting them to further information. That provision is available in the May Logan Centre in South Sefton as well.

LW highlighted that she has seen on social media that there is a Healthwatch England survey for people with Learning Disabilities and their carer's, signposting to People First Merseyside. The question is: do people with learning disabilities feel like healthcare professionals are giving them enough time to explain their problems and recognise the care that they need?

10. Close

The next meeting is on Thursday the 20th March 2025 on Zoom. LW notified the network that she gives her apologies for this meeting as she is away on personal business.