

fading memories affect everyone

“start talking about your mental health”



Independent summary about plans for the future
of mental health services for older people in Surrey,
5 July to 1 October 2010 – compiled by ACW

ACW

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Contents

- 01** Background
- 02** Draft Joint Commissioning Strategy
- 03** The need for a Strategy
- 04** What have people told us they want in our Strategy
- 05** The Draft Strategy: What we are proposing
- 06** Consultation
- 07** Consultation on the Draft Strategy
- 08** Compilation
- 09** Questionnaire Responses
- 10** Survey results – 1st stage responses
- 13** Survey results – 2nd stage responses
- 18** Outreach Events
- 19** Surrey Dementia Summit – 7 July 2010
- 27** Outreach Events
- 37** Summary
- 40** Appendix A – Complete List of Outreach Events

Background



A draft joint commissioning strategy was produced for consultation by the Dementia and Older People's Mental Health Strategy Group, led jointly by NHS Surrey and Surrey County Council. Membership included representation from Surrey and Borders Partnership Foundation Trust, Surrey Community Health, district and borough councils and voluntary organisations.

The purpose of the draft strategy was to present proposals for consultation for the future of dementia and older people's mental health services in Surrey. It will be updated following the consultation period. The draft strategy has been formed taking account of peoples views and included work from both the Dementia & Mental Health Services for Older People in Surrey: Commissioning Strategy Reference Document 2009-14 and Surrey Young Onset Dementia Services Commissioning Strategy Reference Document 2009-14.

The draft strategy describes:

- Why we need to improve services in Surrey for older people with dementia, mental health conditions and their carers
- Why we need a strategy for people with dementia, and older people with mental health conditions
- The strategy: the main things we want to happen over the next five years and what that means for those with dementia, older people with mental health conditions and their carers.

While dementia is a key feature of mental health services for older people (those over 65 years of age), this draft joint commissioning strategy also caters for the full range of mental health needs, including depression and severe mental illness.

The draft strategy includes:

- Mental health services for older people aged 65 and over
- Services that provide treatment, care and support for mental illnesses sometimes known as 'functional', such as depression and anxiety
- Services that provide treatment, care and support for mental illnesses sometimes known as 'organic', such as dementia – including Alzheimer's, vascular dementia, fronto-temporal dementia, Parkinson's disease dementia and Korsakoff's dementia
- Services for the small number of people who experience early onset dementia, meaning those who develop dementia before the age of 65.

The draft strategy excludes:

- Mental health services for people younger than 65 (except people with dementia)
- People with learning disabilities who have developed dementia. Although dementia can have similar symptoms among all people that develop it, the social needs of a person with learning disabilities are likely to be distinctly different from someone who has no recognised learning disability. Therefore we are currently developing a separate strategy to meet these needs.

Dementia and mental ill health in older people is the cause of much suffering and distress that has wide social and economic consequences. These consequences are predicted to significantly increase as people live longer.

Combined with this there is also a common perception amongst the public and a number of professionals that feeling depressed comes with older age and that following a diagnosis of dementia little can be done for the person or their family.

This is not the case; advances in treatments, care and support have been shown to have positive benefits in improving symptoms and general well being.

The strategy

The need to produce a strategy has arisen from talking and consulting with a range of people who have informed us that although there is evidence of lots of good services in Surrey, there is room for improvement and modernisation.

The aim of the strategy is to provide a cohesive five year vision built around the following themes that emerged from our work with a wide range of people and organisations in Surrey, as well as examining the available evidence. These themes are:

Reducing stigma and improving well-being by:

1. Increasing awareness of mental health problems in older people
2. Providing information on what people can do to help themselves.

Improving the quality of people's lives by:

3. Providing early diagnosis, treatment and support in the community
4. Providing intermediate care for older people with mental illness or dementia
5. Improving the quality and effectiveness of inpatient care for older people with mental illness or dementia in general hospitals
6. Improving the quality of long-term care.

We view these themes as our key priorities ensuring we deliver the right services, in the right place at the right time.

Whilst developing the draft strategy, a number of co design events were held to gain an understanding of what older people and their carers want in relation to developing mental health services. We listened to what people in Surrey have told us and have incorporated their views into the draft strategy.

Key themes

- People would like to remain in their own homes and live a healthy life for as long as possible
- People would like information on services that is coordinated and accessible
- When feeling unwell, down, or having difficulty remembering things, people need to know where to go for help
- Getting an accurate diagnosis on an illness is important, to be able to plan for the future
- Carers need to be able to talk to the right people about their situation. They want access to someone with the right expertise who can understand and advise them.
- Carers want to be supported in their caring role, and be well informed about the options available should they need a break from caring
- People don't want to repeat their stories to different professionals. They don't want to go between health and social care services not really knowing where their support comes from and what they are entitled to
- If diagnosed with a mental illness or dementia, people want to understand fully how they can manage their condition
- Services on offer should be available across all of Surrey, no matter what area you live in
- Older people and their carers should be able to get emergency help and support, even outside of working hours
- People should not experience unnecessary admissions and/or extended periods of time in hospital
- Avoiding going into a care home unless a person really needs to
- If an older person with a mental health condition or a person with dementia does need to be looked after in a residential setting, care staff should have a comprehensive understanding of mental illnesses, as well as physical impairments.

NHS Surrey and Surrey County Council are proposing a new 'model of care' that aims to meet the needs of older people with dementia and mental health conditions. A model of care describes how a person's care is provided through a journey known as a 'care pathway'.

The pathway describes how a person's care is provided from assessment, diagnosis and treatment, through to long-term care and support, if that is what they need.

Every older person's needs and their carers will be different; therefore we have developed a range of pathways within our model and have suggested what key elements might be needed..

New Model of care

Our proposed model is based on five 'tiers', each of which reflects the level of support that might be required, based on needs. Whilst the tiers represent differing levels of need it does not mean a person's journey through the tiers is a linear one. A person with dementia or an older person with a mental illness can effectively move from one tier to the next, or the last, skip a tier out. What service an older person or their carer receives is based on need and choice of care that suits them best.

This new model of care differs from the way services have been provided in the past and takes into account what people have told us and the recommendations from best practice.

In future we want less emphasis on the use of hospital and residential care and more of an emphasis on assessment, treatment and care in people's own homes.

The model would also have greater emphasis than previously on: those with low and moderate needs and the older population in general; and services working together across sectors in offering more support.

However, conditions such as dementia are progressive and the strategy will address ways to improve the quality of care for those with complex needs, such as those who may need long term residential care. We aim to meet people's needs with the right services, in the right place at the right time.

To ensure the consultation is a success relies on the involvement of as many people from Surrey as possible. Not only those directly and indirectly affected by mental health issues, but the different organisations and carers, all working together to achieve one goal.

In part, this is down to the engagement activities and those involved, but also in formulating a strong message that is attractive and stimulating – to engage, educate and involve as many people as possible.

This involvement will ultimately ensure the consultation process is a successful one and as wide a range of responses received as is appropriate, to ensure a complete picture of peoples needs and requirements as possible.

Key Challenges

- Running a consultation process that is perceived as clear, accessible and a real opportunity for local people to make their views known.
- Acknowledging and addressing local fears and concerns about change in the context of previous local consultations.
- Educating the general public about dementia and also reaching out to key people not usually considered in outreach campaigns.
- Building public trust and confidence in how health and social care services can be delivered in alternative ways, with the emphasis on community-based services, in ways that are clinically safe while fully meeting their needs.
- Producing a document that describes the new model of care from the point of view of the person, carer and health and social care worker.
- The average age of the population in Surrey is rising, partly due to generally high fitness levels and good health.
- There is a highly transient working population in Surrey, with the result of them having little time to spend at consultative events.
- We need to ascertain and better respond to current and future needs.

Strategic Aims

- Consultation must not be limited to the patient, carer or health care professional.
- Action needs to be clear, honest and transparent. Stating the problems, goals, and short and long term aims. This will assure that the service is people-led and engage those involved in believing that not only can their involvement assist but also shape future needs and services.
- It is especially important that the future care pathways are clearly delineated and individual choice paramount.
- Education of the demographic needs to clearly demonstrate the difference between dementia and mental health problems and illness.

ACW was contracted to coordinate the 12 week public consultation which ended on the 1st October.

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A campaign message was formulated and a range of appropriate imagery was sourced to run alongside the informative text and case studies. It was felt that a strong, simple message that attracted as much attention as possible was preferable to a weaker, more generic statement and imagery.

Consultation Documents and Questionnaire

ACW, in conjunction with NHS Surrey and Surrey County Council produced a summary version of the draft strategy for consultation along with a series of short questions, presented in an easily understandable format. This consisted of a paper-based and an online questionnaire designed to obtain views and opinions on various mental health issues and services to determine if the draft strategy is correct in its assumptions and facilitate feedback on how improvement can be made.

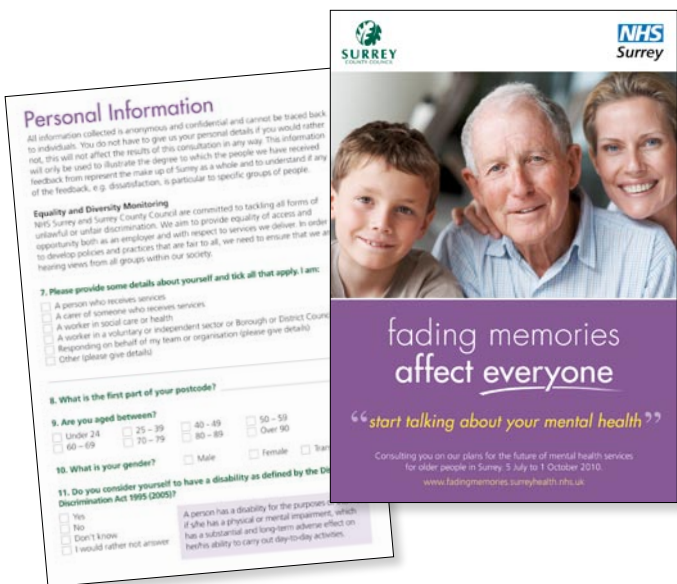
The questionnaire was tailored in two different ways:

- Detailed paper-based form for general consumption
- Detailed online version.

These two platforms allowed us to make the most of our opportunities by 'venue', 'environment' and 'time available'. In summary the consultation documents included an easy read summary document and questionnaire, the Draft Strategy and two supporting reference documents.

Group meetings

In addition to the information gathered via the questionnaire there were other public and group events held at multiple venues throughout the 11 districts and boroughs within Surrey, where people were encouraged to fill in the questionnaire or submit their comments formally. All of these views were logged as formal responses to the consultation.



Summary Document and questionnaire sample pages

The key themes from the responses were collated by ACW; an independent organisation specialising in analysing feedback, reviewing evidence based practice and undertaking evaluations and research for the health care sector and third party organisations in the UK and overseas.

The ACW team includes social marketing experts, researchers and analysts. The independent compilation team was not involved in the development of the proposed model of care or the consultation process itself.

Collecting responses

NHS Surrey acted as the hub for receiving all written and emailed responses. ACW have collated all the responses, paper-based and web and collated answers and findings and trends as follows. Each question will be dealt with in both isolation and collectively, where appropriate, with accompanying rationale.

Analysing responses

Two members of the compilation team independently read all responses, identified key themes and created an electronic summary of every response. This ensured a robust and consistent approach. Demographic characteristics such as geographic location were noted to allow comparisons.

The analysis involved qualitative and quantitative methods. Qualitative theme analysis based on a grounded theory approach was used to examine key messages. This means that the main themes built on the exact words and perspectives of responses themselves.

Quotes have been used to illustrate points throughout this report, however the quotes used are not necessarily 'true' or factual. They are used to represent the views in responses, not to suggest that the views expressed are accurate or unquestionable.

To provide additional rigour, quantitative analysis was used. Every key point was converted to a numerical code to make it easier to quantify the most commonly mentioned issues.



Consultation microsite – home page

Questionnaire Responses

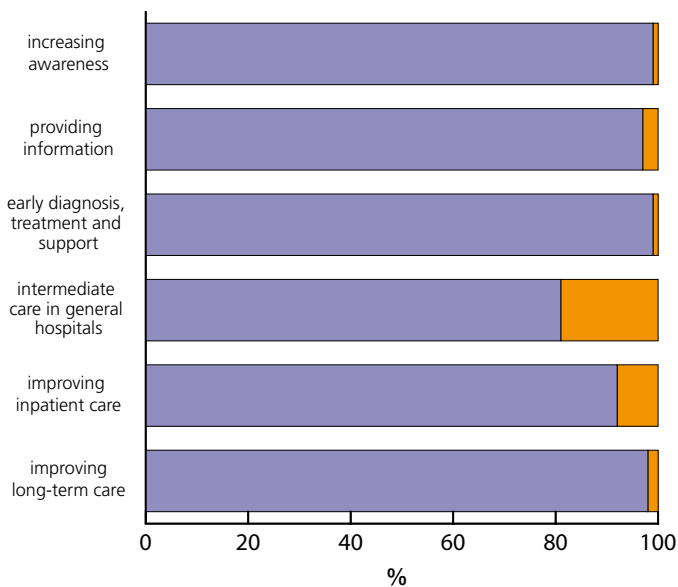


Consultation Feedback

This information is used to illustrate the degree to which the people we have received feedback from represent the make up of Surrey as a whole and to note the direct feedback and general comments.

135 people responded via the questionnaire in the survey and the results and findings are as below:

Figure 1: do you agree with the priorities we have chosen for Surrey?



There were a total of 135 responses, of which the majority agreed with the priorities chosen for Surrey.

■ Yes ■ No

1. Do you agree with the priorities we have chosen for Surrey?

Of the 135 responses (see Figure 1) 99% agreed with the priorities chosen for Surrey to increase awareness of mental health problems in older people and to provide early diagnosis treatment and support in the community. 98% were in agreement with the priorities of providing information on what people can do to help themselves and providing intermediate care and improving the quality of long-term care, whilst 92% of responses were in agreement with improving the quality of inpatient care.

Comments from others

A selection of typical responses from people who disagreed with the statements above:

- better to have special wards or hospitals to treat mental illness or dementia as specialist care is needed
- people suffering from dementia are unlikely to be able to understand (or remember) information how to help themselves
- puts too much responsibility on the carer who is already tired, worried and at the end of their tether

Please give us any comments on how Local Health, Social Care and Community Services could be improved over the next 5 years for older people with mental health issues?

A selection of responses ranked by preference:

- more information, advice and support for care workers, staff and families
- better partnership between health and social services
- appropriate, effective dementia workshops/training for front-line healthcare staff

2. Do you agree with our proposals to ensure whenever possible assessment, treatment and care is provided in people's own homes rather than in hospital or residential care.

90% of the participants said Yes to the proposals and 10% answered No.

Comments from others

A selection of responses from people who answered No, ranked in order of preference:

- it will be putting a strain on family members who will become carers even if they do not want to
- people with dementia are much happier within their own environment, keeping to their own routine amongst things that are familiar to them
- only if the home is suitable

3. Do you agree with our proposal to put more money into treating people with low and moderate needs.

Of the responses from individuals, 95% agreed with the proposals and 5% disagreed.

Comments from others

A selection of typical responses ranked by preference:

- I think the funding should be evenly spread out across all levels of need
- absolutely, if these needs are ignored then it's a problem for the future
- difficult to argue against but does this mean less money for those with severe needs?

4. Do you agree with our proposal to release money needed for increased prevention and improved care services in the community by reducing inpatient beds in mental health and general hospitals?

70% of respondees said Yes to the proposals, with only the remaining 30% saying No.

Comments from others

A selection of typical responses ranked by preference:

- there will always be a need for inpatient beds within mental health to save lives of the vulnerable
- depends on the needs of the service user and their risk assessments in relation to their safety and that of the public
- many patients cannot cope in the community

5. If you were receiving healthcare in your own home / in the community over a long period of time.

The top three statements ranked in order of importance:

- being supported to continue my day-to-day activities such as work or social commitments
- being able to have choices about how my care is managed and supported
- having information about what I can do to manage my health

Comments from others

A selection of typical responses ranked by preference:

- involvement of / support for families and carers
- to be accepted in the community and not have the social stigma attached to mental health issues
- having trained, competent and caring staff
- communication between providers

6. Health services should be focused on the individual receiving them and be provided in a range of settings.

The top three statements ranked in order of importance:

- I know that the member of staff is a specialist in their field
- I can see the same member of staff at each appointment
- I am given the time I need to talk about my healthcare

Comments from others

A selection of typical responses ranked by preference:

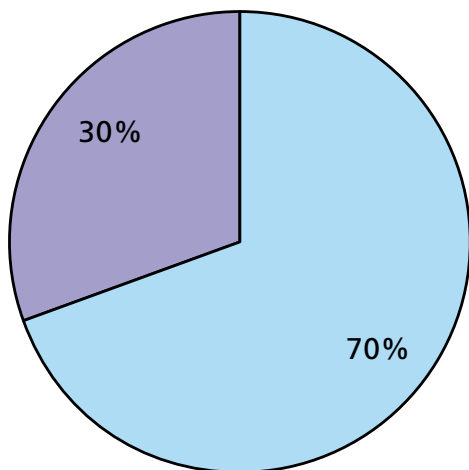
- awareness of travel needs to / from appointments
- should be person centred to suit needs of the patient
- patient notes should be available at appointments
- involve the carer / family member as they are the ones who usually plan everything

Personal Information

This section gives insight into the demographic background of participants taking part in the survey. The more widespread the demographics the more valid the results in representing Surrey's diverse population.

135 people responded via the questionnaire in the survey and the results and findings are as below:

Figure 2: responses by type



There were a total of 135 responses, of which 94 were paper-based and 41 were submitted online.

- Feedback form
- Online form

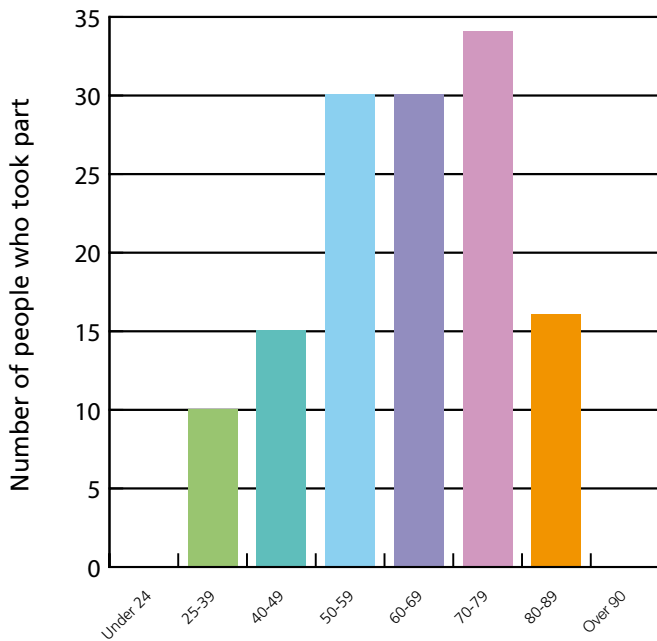
Responses by type

The figure for respondees is unusually high from the online form. Typically, in surveys of this type, we would expect the figure to be around 15%.

This may be an atypical response or we could conclude that the number of online responses were normal and responses were lower than anticipated elsewhere.

However, this is offset by the range and extent of direct responses from individuals, groups and organisations that responded throughout all 11 Surrey boroughs.





Graph shows the age groups of the people who took part in our survey.

- Under 24
- 25-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80-89
- Over 90

Responses by age

The majority of participants (see Figure 3) that responded (over 69%) were in the age range of 50-79, just under 12% were 80-89 and 18.5% were aged 25-49. Slightly disappointingly, no-one under 24 or over 90 responded to the survey.

Responses by gender

Of the responses from individuals, 72% were from women and 28% were from men.

Responses by disability

16% of respondents considered themselves disabled in some way, while 76% did not – although the particular disability was not ascertained.

Responses by ethnicity

90% of the people that provided information about their ethnic group were White and just under 5% were Asian. Under 2% were from other ethnic groups.

Responses by faith

87% of respondees were Christian and 4% either Hindu / Muslim. 9% made up the remaining.



Figure 4: location of responses

| Area/Borough of Surrey | Postcodes | % |
|------------------------|-----------------------------|----|
| Elmbridge | KT8, KT10, KT11, KT12, KT13 | 11 |
| Epsom and Ewell | KT17-KT19 | 5 |
| Guildford | GU1 - GU5 | 10 |
| Mole Valley | KT21, KT22-KT24, RH4, RH5 | 7 |
| Reigate and Banstead | KT20, RH1, RH2, RH6, SM7 | 11 |
| Runnymede | KT15, KT16, GU25, TW20 | 9 |
| Spelthorne | TW15, TW17, TW18-TW19 | 11 |
| Surrey Heath | GU15, GU18 | 3 |
| Tandridge | CR3, CR6, RH8 | 3 |
| Waverley | GU6, GU7-GU8, GU9-GU10 | 9 |
| Woking | GU21 - GU24, KT14 | 12 |

| Outside Surrey - Areas | Postcodes | % |
|------------------------|-------------|---|
| Kingston-Upon-Thames | KT2 | 1 |
| Aldershot | GU11 - GU12 | 1 |
| Farnborough | GU14 | 1 |
| Bordon | GU35 | 1 |
| Fleet | GU51 | 1 |
| Coulsdon | CR5 | 1 |
| Battersea | SW8 | 1 |

Location of responses

To simplify the data received by postcode we have grouped into Districts and Boroughs. The majority of respondees were predominantly from the larger areas of Woking, Elmbridge, Reigate & Banstead, Spelthorne, Guildford, Runnymede and Waverley.

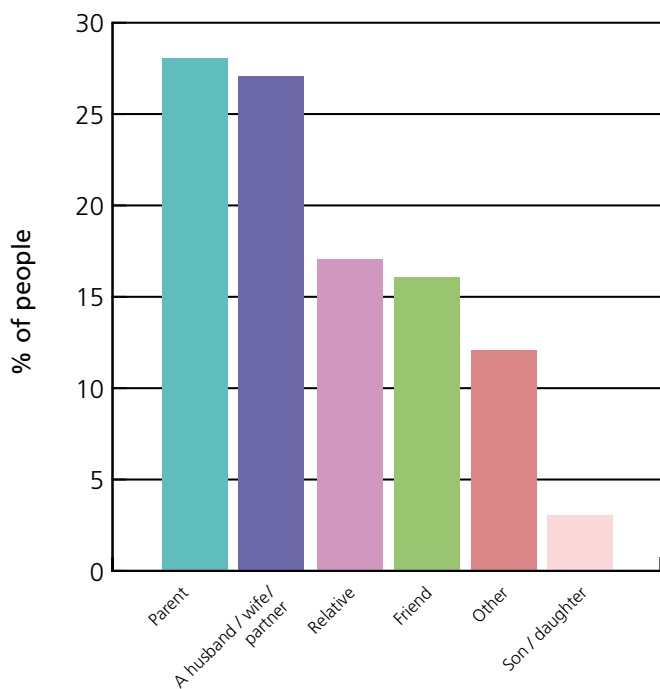
Only 7% of responses were by people outside the 11 districts and boroughs within Surrey.



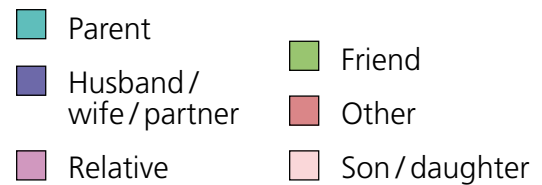
Worried about memory or mental health

Three-quarters of the people that filled in the form said they were worried about someone else's memory or mental health.

Figure 5: worried about someone else's memory or mental health



This graph shows who, with memory or mental health problems, people are worried about.

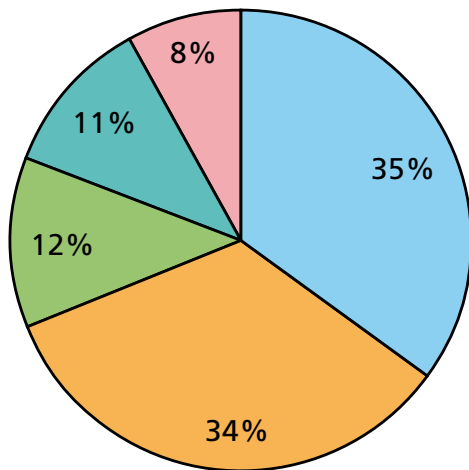


Comments from others

A selection of typical responses from people outside the category are stated below:

- local community welfare
- clients
- people generally
- carers
- older people
- patients
- community volunteer

Figure 6: types of person cared for with mental health issues



Graph shows the relationship of people cared for with mental health issues.

- Parent
- Husband/wife/partner
- Other
- Relative
- Friend

Types of person cared for with mental health issues

To ascertain the types of people predominantly cared for we asked carers to state who their cared for were. The largest two groups were, predictably, parent or husband/wife/partner, at 35% and 34% respectively.

The family unit was further represented by 11% of relatives; amounting to a total of 80% of people cared for from the family unit.

8% of people cared for were friends while only 12% make up the rest.

Comments from others

A selection of typical responses from people outside the category are stated below:

- Liaison Nurse – I assess mental health patients at the Hospital
- supporting rather than “caring” in a hands on manner – telephone prompting, mood monitoring, trying to enrich and enhance their lives
- local community
- mental health social group
- service users
- patients / clients

Outreach Events



On 7th July, a stakeholder event 'Surrey Dementia Summit' was held, as part of National Dementia Week. This event saw both the formal launch of the draft strategy consultation and a wider consultation on the National Dementia Strategy.

The summit was organised by Surrey County Council, NHS Surrey, Surrey and Borders Partnership NHS Foundation Trust, Alzheimer's Society Surrey, Action for Carers Surrey, Surrey Local Involvement Network, district and borough councils and acute hospital trusts.

Informing you

Professor Sube Banerjee, Consultant Psychiatrist led the development of the National Dementia Strategy and was the keynote speaker the summit, endorsing a co-ordinated approach to caring for people with dementia. Sube gave a talk based on the national strategy that recommended improving public awareness about the condition and making sure people affected by Dementia receive an early diagnosis.

He was joined on the day by professor Alistair Burns, who took up the post of National Clinical Director for Dementia in April to lead the implementation of the strategy. After listening to stakeholders, Alistair had some positive reflections on the enthusiasm and drive that we have in Surrey, and also identified the key challenges we face in the future.

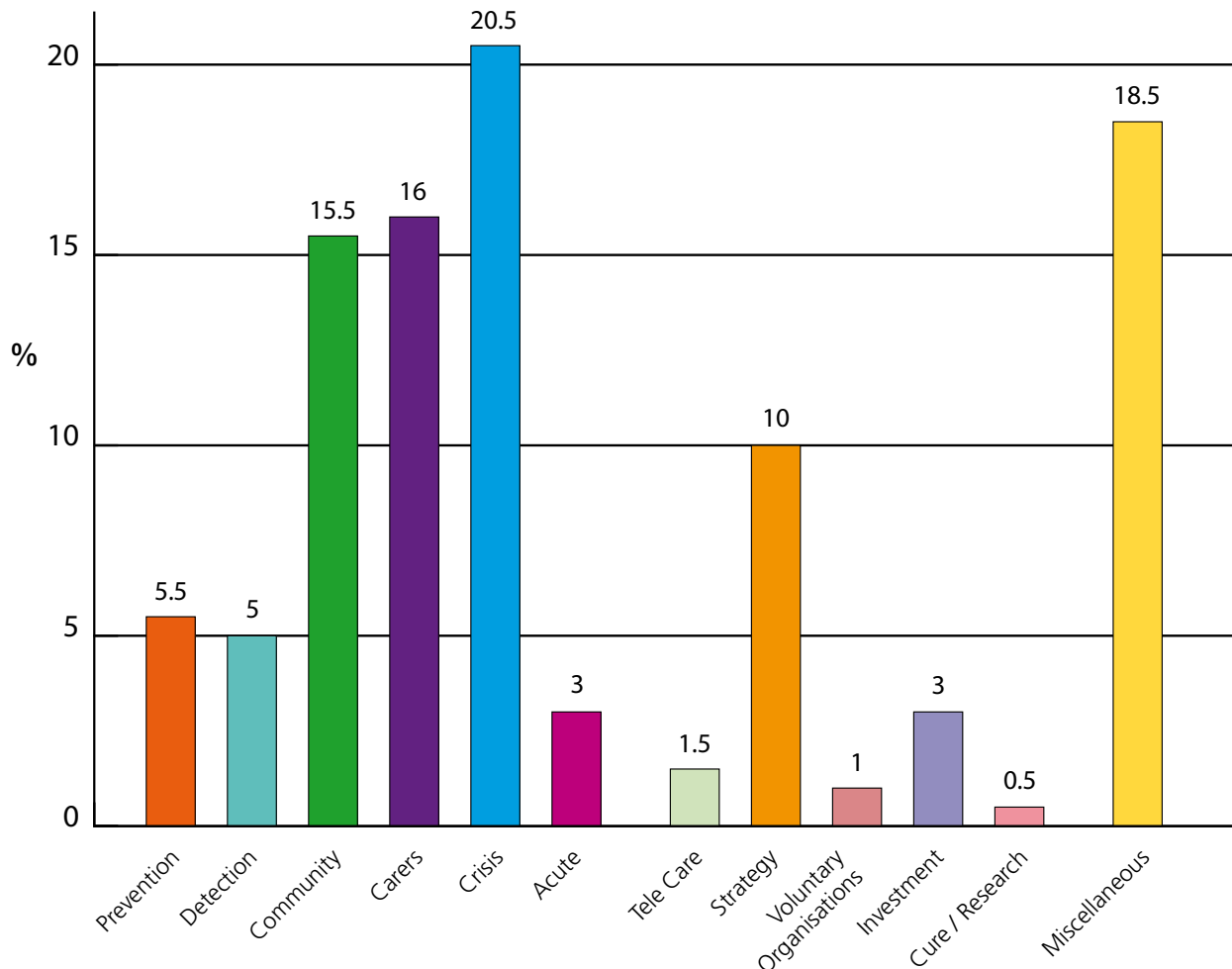
Engaging with you

The summit was organised to engage and listen to the views of people with an interest in dementia services including people with dementia, carers and staff to help us plan how we develop our services in the future.

Capturing expectations

At the outset of the day delegates were invited to discuss within their table groups what they hoped to achieve from the Summit. Delegates captured their individual thoughts on notes. They were then given an opportunity to stick onto posters surrounding the room which were titled "What we Hope to Achieve Together Today" and "Our Hopes and Fears". There were a total of 361 separate responses covering a very wide range of topics. We classified the responses primarily into the six broad main engagement themes, we then categorised the next most common with other miscellaneous comments outside this.

Figure 7: feedback into categories by percentage of responses



a. Prevention and raising awareness

General concerns appropriate to this category:

- A deeper understanding of the lived experience of people with dementia
- To provide an alternative view on living with dementia and raise awareness of the support available
- Mobilising Surrey to focus on dementia and get engaging as the key priority
- How will stigma be challenged?
- A greater knowledge about dementia and its effects on the family
- Clear information for older people before dementia occurs
- The overall strategy – First symptoms of dementia
- Prevention and how to raise awareness
- What can we take back to our teams to promote Dementia awareness?
- Plans to engage the Community at large in the issues surrounding dementia.

b. Detection and diagnosis

General concerns appropriate to this category:

- Knowledge of the early signs that someone may have dementia
- Physical health problems of people with dementia are diagnosed and care delivered; bearing in mind; the multiple pathology on elderly
- More monitoring of safeguarding vulnerable adults and not enough support
- To increase the rate of diagnosis of Dementia in Surrey
- Different behaviours associated with dementia
- Communication with a person with dementia
- Awareness of problems encountered by people with dementia
- Focus on early identification and treatment
- More info related to how Surrey will move forward with information shared today!
- A better understanding of what services are available and what needs to be developed.

c. Living well in the community with dementia

General concerns appropriate to this category:

- Support groups and carers groups need to be more accessible to everyone to give families and carers who are looking after someone with dementia more respite and support
- Specialist training for home care providers is crucial for people to continue living at home
- Specialist services need to be in place for people with early onset dementia as well as learning disabilities
- The strategy needs to have more detail on what the proposals will mean for self directed support
- Transport is essential, and needs to be explored more. Smaller community opportunities should be available to take services to people
- The proposed memory clinics could have more of a social side, to encourage people to attend and reduce the stigma associated with them
- Knowledge of the Voluntary services we can call on to support people with dementia (and their Carers)

- Rehabilitation teams - Identifying the need for specialised services, therapists to work with people with dementia to maximise their quality of life and give them the opportunity at rehabilitation services
- How will people with Learning Disabilities and Dementia fit into the Social Care Strategy. Are there any specific provisions for this group?
- Knowledge of training opportunities for people working with dementia.

d. Supporting carers of people with dementia

General concerns appropriate to this category:

- Respite breaks are critical for carers of people with dementia. Support should be personalised to suit individual needs, since people who have dementia cope with it in many different ways
- The proposed dementia advisor role will be key for carers
- GPs must develop a greater understanding of dementia so that they can be of support to families and carers
- Admiral nurses are a lifeline for carers and the strategy should consider commissioning these further
- Carers need more specialised training to deal with people with dementia
- To hear the views of users of services, from those with dementia and from carers
- To help support the carers to provide the level and individual service that our clients require and need to have a good quality of life based around their individual needs
- What support and training is there for Care workers in the community? How do we access this?
- To understand the role of other providers to be able to access facilities or support to enable and promote independence for Clients we support in their own homes
- GPs/ Professionals to recognise that carers as the disease progresses know as much as the professional, and can provide valuable information.

e. What should happen in a crisis

General concerns appropriate to this category:

- All agencies should be working more closely together
- Sharing practice and information across agencies is key
- Combined physical and mental health teams to triage dementia and physical health
- Training needed for paramedics and ambulance services need to be included in care pathway planning
- Ensure a full review on referral to reduce risk (physical, mental health and medication)
- Rehab/step-down for people on discharge from acute hospital should be standard
- A thorough and robust carers assessment should always be offered
- Mental health professionals should be part of intermediate care teams in Surrey
- More reliable respite is needed to reduce the risk of some crises from occurring
- Meeting health professionals who are keen to really improve the lives of people living with dementia. Networking of services to allow people to stay within their own homes who have dementia
- Take forward discussions on integration of Health and Social Care teams in delivery of dementia care
- Be open minded and really work together.

f. Caring for people with dementia in acute hospital

General concerns appropriate to this category:

- There should be swift, joint assessments (physical and mental health)
- Understanding the needs and behaviours of people with dementia better
- A review of training for all staff in acute hospitals should be undertaken
- More specialised training for staff so that they can deal with people who are suffering from dementia. Could allocate targeted time for people with dementia
- Express concerns about treatment of dementia sufferers in hospitals

- End of life to ensure support for Carers when their loved one has passed away
- Increased recognition and the commitment to take action on improving hospital care within Surrey for people with dementia
- Understanding dementia and how to treat people within the Acute sector
- Involvement of Voluntary sector within Acute hospital setting
- Training for Healthcare Professionals in the Acute Sector - re: Dementia.

Responses outside the main categories

In addition to the initial six categories there were comments that fell outside and these have been grouped into, in no particular order;

- Telecare
- Strategy
- Voluntary Organisations
- Investment / funding
- Dementia cure / research

g. Telecare

General concerns appropriate to this category:

- More knowledge of telecare services available to people in the community
- Why keep changing Community Alarm telecare – changed to Chubb – less effective in Tandridge
- Telecare awareness
- Telecare staff
- Is Telecare in Surrey's strategy?

h. Strategy

General concerns appropriate to this category:

- The five year Health and Social Care Strategy aims to help people live in their homes for longer.
- Know the national strategy for supporting people affected by dementia
- Understanding of the National Dementia Strategy
- A real recognition that the solutions and the people to deliver them are in the room – that People / Patients come first, that service alignment comes second and Organisations/Institutions third
- A strategy that motivates professionals and carers and produces action
- Understand the model of partnership working used here in Surrey, so we can take the best bits back to Kent and Sussex as well
- To provide an adequate care plan for people with dementia and to ensure all their needs are being met.
- Not changing those elements of the service that already work well – just focus on those bits that required development/improvement
- Learn more about the Dementia strategy and how we will achieve and maintain key principles
- How will you ensure patients views are at the centre of all decisions?

i. Voluntary Organisations

General concerns appropriate to this category:

- Get support and referrals to the “Friends with Dementia” project in Woking.
- Better understanding of what the Voluntary and Charitable sectors can provide within current resources
- How local Borough based charities can be involved?
- Talk to voluntary organisations about what help they provide and how to access the help.

j. Investment

General concerns appropriate to this category:

- To have reassurance that services; will be allocated suitable funding from PCT/La's to be able to provide quality care and support for people who have dementia
- Clear directions on where the money / funding is, how I get it to implement the Nation Dementia Strategy
- Money! Put into health dementia care – at present most of the CMHT's are “overloaded” trying to give good-quality care with limited resources
- Financial commitment by NHS Surrey to implement strategy for Older Adults Mental Health
- Genuine financial commitment from NHS Surrey. Must be ring fenced.
- Investment in services – time and effort not just what we usually get words as I know there is little money. We need action now – have had talk over many years.
- Where is the money to support the Strategy?
- Financial support
- “How we achieve an improved service with reduced costs.”

k. Cure / Research

General concerns appropriate to this category:

- Researches being carried out to develop new drugs for the prevention of dementia to progress
- Cure for dementia.

I. Miscellaneous

General concerns appropriate to this category:

- An acknowledgement that the way we currently do business is failing people with dementia and that there is a (unreadable) imperative to do things better.
- Publicise elder abuse
- I would like to share my own experience and to hear from others, regarding working with down's carers with dementia or when supporting someone with dementia
- How the private sector can support the NHS and Social Care.
- I want consistency of outcomes for people
- Actually achieving something from today – there have been Dementia Conferences in the past which have gone nowhere in terms of actions
- Out of hours service for Older Adult Mental Health Teams
- Return to note taking for messages and not voicemail. Takes time to do it and listen to all the messages before taking action – crisis often over
- More and better for less
- Dignity and time and support for all.

Hopes:-

General concerns appropriate to this category:

- Hopes:- a Dementia Care Service Contract is
 - Equitable
 - Available
 - High Quality
 - User / Carer centred.
- Hope:- Take the messages, particularly from Dr Sube Banerjee and make them happen in Surrey
- Hope:- Carers will get the information and support they need to support their caring role and are recognised as point partners
- Hope:- Profile for Dementia is kept on Government agenda
- Hope: Services for Early Onset of Dementia, developed and monies made available to enable work to support people and carers

- Hope: Management of Dementia is done early to delay worsening symptoms
- Hope:- Will the Strategy affect/interface with acute inpatient services.

Fears:-

General concerns appropriate to this category:

- Fears:- Lack of finance will be the downfall of implementing the strategy
- Fears:- Don't forget people's physical health
- Fear:- Barriers will get in the way of actions
- Fear:- Still some reluctance, particularly by medics, to full involvement and "Sharing" with Carers
- Fear:- Dementia drops off radar, government withdrawing monies from services. Services close!
- My fear: To 'live' with Dementia, to 'live' like Elsie the Carer. Elsie made me cry. Joined up care and support should be priority.

Workshop Feedback

Six workshop sessions were held throughout the day, giving people the chance to discuss various elements of both the National Dementia and our draft strategy. The workshops were facilitated by members of the multi-agency strategy group and from the feedback we received, the main themes across all discussions were:

Prevention and raising awareness

- We need to recognise and celebrate the positive services and successful support that we currently provide
- There is a need to understand dementia and how the risk of developing it can be reduced
- People need to know you can live well with dementia and there is a life to be lived after diagnosis
- Awareness campaigns should include clarity on symptoms and what can happen, and equally what might not happen.

- We should aim to treat dementia as we would any other long-term illness – understanding information available, working at it, and working alongside clinicians

Detection and diagnosis

- Dementia deserves the same level of attention and awareness raising as other conditions such as stroke, for example the FAST campaign
- It is important for all professionals and the public to understand the different reasons for 'dementia-type' symptoms, including other mental illnesses such as depression, or a physical impairment for example high blood pressure
- Need a comprehensive training programme for all staff, as well as family carers and support staff and remember that diagnosis is not the end. This includes everyone involved or who may come into contact with people with dementia. Training should include communication tools, managing behaviours, understanding symptoms and early warning signs

GPs have a crucial role to play in detecting dementia, therefore there should be an agreed training programme specifically designed for them

- Advice should be available immediately after someone is diagnosed with dementia.

Living well in the community with dementia

- Support groups and carers groups are not the only answer and that these options are not appropriate for everyone, since some cannot get respite to access this type of support
- Specialist training for home care providers is crucial for people to continue living at home. There is a need explore how to stimulate the market to provide this
- Specialist services and expertise for people with early onset dementia and learning disabilities needs to be developed, as this is variable across Surrey currently. Also important to distinguish between age groups.
- The strategy needs to have more detail on what the proposals will mean for self directed support.
- Transport is essential, and needs to be explored more fully. Smaller community opportunities should be available to take services to people.

- The proposed memory clinics could have more of a social side, to encourage people to attend and reduce the stigma associated with them.

Supporting carers of people with dementia

- The strategy needs to look in detail at best practice examples of support for carers, since services vary greatly in Surrey
- Breaks are critical for carers of people with dementia. Support should be personalised, since people who have dementia experience it in many different ways
- The proposed dementia advisor role will be key for carers
- Work needs to be done to engage GPs around knowledge and support for carers
- The strategy could build on the successful work of 'information prescriptions' for carers
- Admiral nurses are a lifeline for carers and the strategy should consider commissioning these further
- Carers need training specific for dementia, as do professionals.

What should happen in a crisis?

- Need a whole systems approach to crisis – all agencies should be working together
- Sharing practice and information across agencies is key to reducing the risk of a crisis
- Combined physical and mental health teams to triage dementia and physical health
- Training needed for paramedics and ambulance services need to be included in care pathway planning
- Ensure full review on referral to reduce risk (physical, mental health and medication)
- Rehab/step-down for people on discharge from acute hospital should be standard
- A thorough and robust carers assessment should always be offered
- Mental health professionals should be part of intermediate care teams in Surrey
- More reliable respite is needed to reduce the risk of some crises from occurring.

Caring for people with Dementia in acute hospital

- There should be swift, joint assessments (physical and mental health)
- Staff in acute hospitals need to understand the needs and behaviours of people with dementia better. Simple things such as food, special help for example red trays
Hospitals should take advantage of expert advice from family members
- Also use 'Life books' for more person centred care
A review of training for all staff in acute hospitals should be undertaken
- Could allocate targeted time for people with dementia
Ideally acute hospitals would have an in-house specialist older people's mental health team to provide the training to all staff, as well as prevention and care.

A total of 54 Outreach Events were conducted throughout all 11 District and Boroughs, with a range of stakeholders such as, Surrey LINKs, Community Centres, Alzheimer's Society, Ambulance Service, Civic Centres, Hospitals, Older People Forums, Shopping Centres, Festivals, Community Centres, Surrey Care Associations, Care Homes, Equality and Diversity Forum and Woking Mosque (see Appendix A for complete list).

Many people and organisations throughout Surrey responded in detail with their individual concerns and a summary of the feedback is noted on the following pages.

Table 1: health promotion

| Health Promotion |
|---|
| • Information on how people can help themselves |
| • Information needs to be presented in an easy to understand way |
| • Advantageous if all those in the NHS, Social Services and Charities communicated with each other and were then able to pass on the relevant information to carers |
| • Needs of those with literacy problems need to be addressed |
| • Mental health information should be more widely available with reference to those with Learning Disabilities or language issues |
| • Information is made available more widely e.g. Supermarkets, chemists, schools and possibly to all households |
| • Public education focused on getting a caring community |
| • Health Promotion – also be accessible for people with Learning Disabilities |

Table 2: primary and community care

| Primary and Community Care |
|--|
| <p>Early diagnosis, treatment and community support:</p> <ul style="list-style-type: none"> • Crucial to address the 3 in 4 people that have mental health problems but are not diagnosed. Diagnosis must be linked with appropriate medication at the start |
| <ul style="list-style-type: none"> • Not all GPs are sympathetic or knowledgeable about dementia |
| <ul style="list-style-type: none"> • Address difficulties with the GP service before role is extended |
| <ul style="list-style-type: none"> • General public need to be educated on what they can do to help not only those with dementia and older people with mental illness, but also their carers |
| <ul style="list-style-type: none"> • Carers, family and friends must need to be more engaged and involved with the patients care pathway |
| <ul style="list-style-type: none"> • Talking therapies for older people need to be considered more thoroughly and need to be personalised in terms of access and time spent |
| <ul style="list-style-type: none"> • Ideally, older people should be offered this service in their own homes |
| <ul style="list-style-type: none"> • Concern that Older People's Community Mental Health Team's may receive higher referrals for those with memory problems that IAPT doesn't cover |
| <ul style="list-style-type: none"> • People with mental health tier 2 psychological therapies will not have access to secondary mental health services |
| <ul style="list-style-type: none"> • Long waits for counselling in mental health (4 months), it'll be on a basis of clinical need not a social care need |

Table 3: intermediate care

| Intermediate Care |
|---|
| • It must clear that not everyone will need this service |
| • Alteration of payment method for local Alzheimer's Day Care have not been well communicated Transition to Older People's Teams, from under 65 mental health services to older people's mental health teams. Support can differ between teams |
| • There are not enough informed people to talk to |
| • Need someone you can ring during a crisis |
| • Transport is a big problem |
| • Care assistants and care managers are not trained properly |
| • Respite – no centre for people under 65 yrs in my area – staffed and financed properly, more Surrey County Council control over the way it is managed |
| • Good day services and respite mean less people in residential care |
| • Flexible day care and respite for those not in residential |
| • Day care has to be meaningful, not just sitting around |
| • Education / training for care staff, social workers and carer support is vital |
| • Ensuring services are fit for purpose |

Table 4: hospital inpatient care

| Hospital Inpatient Care |
|--|
| <ul style="list-style-type: none"> Needs to be a better co-ordination between the services |
| <ul style="list-style-type: none"> Pleased that Ashford and St Peters hospital are piloting a specific Dementia ward |
| <p>For people that were receiving healthcare in your own home / in the community over a long period of time the most important issues for them were;</p> <ul style="list-style-type: none"> Being able to decide the time that regular appointments take place |
| <ul style="list-style-type: none"> Being able to decide where regular appointments take place |
| <ul style="list-style-type: none"> Being supported to continue my day-to-day activities such as work or social commitments |
| <p>Health services should be focused on the individual receiving them and be provided in a range of settings:</p> <ul style="list-style-type: none"> I can easily find my way to an appointment |

Table 5: long term care

| Long Term care |
|--|
| <p>When care is provided in the persons own home it needs to be applied where appropriate and to individual's circumstances</p> <ul style="list-style-type: none"> Health and abilities of the carer must be taken into account |
| <ul style="list-style-type: none"> When assessment, treatment and care cannot be provided at home there must be resources available within the Acute sector |
| <ul style="list-style-type: none"> What is the situation of a husband or wife who needs nursing home care and their money runs out? |
| <p>Professionals in Domiciliary Care felt positive about the draft strategy</p> <ul style="list-style-type: none"> There are concerns about the inference that older people will have to exhaust all options before the residential care is agreed |
| <ul style="list-style-type: none"> No indication of how care homes support is going to be funded |

Table 6: medication

| Medication |
|---|
| <ul style="list-style-type: none"> • There is no mention in the strategy of medication. What is the current situation and is this set to change? |
| <ul style="list-style-type: none"> • Concerns over the eligibility for medication for aggression – there needs to be an improved scoring process |
| <ul style="list-style-type: none"> • Side effects of drugs need to be fully explained |

Table 7: early onset dementia

| Early Onset Dementia |
|--|
| <ul style="list-style-type: none"> • Money must not be shifted at the expense of people with mental health illnesses who are younger |
| <ul style="list-style-type: none"> • Little mention in the strategy and failure to account for younger people with dementia |
| <ul style="list-style-type: none"> • Concerns over young onset dementia clinics at Farnham and Epsom closed! |
| <ul style="list-style-type: none"> • At the early onset of dementia it is very important that prognosis and the pathway are discussed at length |

Table 8: learning disabilities

| Learning Disabilities |
|---|
| • Needs to be special facilities for those people who have both learning disabilities and dementia |
| • I am very concerned that people with learning Disability who develop dementia are not included in this strategy |
| • Older people with a learning disability, where do they fit in to mental health services? |
| • Short term breaks should be a mixture of daytime breaks and weekly breaks (more than once or twice a year) |
| • Carers Needs Assessments are important |
| • Carers health paramount – both mental health and physical |
| • There is great fear amongst Carers that if the person is moved away from home, that there will not be enough care |
| • Awareness of people at greater risk of developing dementia e.g. family history of young onset dementia, Down's Syndrome, AIDS sufferers, chronic alcoholics, Parkinsons disease |
| • Figures for many people with Down Syndrome have dementia in Surrey |
| • Majority of care for people with Learning Disabilities is within paid services and not with family carers |
| • Ongoing help and advice service needs to be funded |
| • Limited vacancies in dementia friendly accommodation |
| • Lack of dementia friendly short breaks facilities |
| • Generic older peoples services currently not appropriate for people with learning disabilities and dementia |

Table 9: mental illness

| Mental Illness |
|--|
| <ul style="list-style-type: none">• Mental illnesses, other than dementia need to be recognised and implications for service provision considered |
| <ul style="list-style-type: none">• Mental Illness needs a consultation event with same momentum as the dementia summit. Particularly as the most common mental illness among older people is Depression |
| <ul style="list-style-type: none">• The strategy is welcomed - the Older People's service in Surrey has trailed well behind the "Working Age Adult service" |
| <ul style="list-style-type: none">• Little in the way of specific services for people with depression and alcohol abuse |

Table 10: carers

| Carers |
|---|
| • Carers should, up to a point, have same training as staff |
| • Carers need practical tips in training – how do you get some one into a shower if they are resistant? How do you cope with challenging behaviour? |
| • Carers need to be able to understand different symptoms, know what to expect at the next stage |
| • Carers do not get any recognition or acknowledgment |
| • Concerns the strategy does not address issues of isolation for those that do not have an extended family, friends or resources or access other community services |
| • Communicate to carers everything available |
| • Statistics on carers in do not reflect number of carers who are of working age (80%), 58% of carers do not live with the person they care for |
| • No mention of young carers or support for children |
| • Talk about Carers in way that they would want i.e. “Carers are able to access assessment and services” |
| • Little about access to Welfare Benefits for carer’s |
| • Services to support Carers independence as well as breaks |
| • Dementia patients on general wards – a real no no |
| • Little about stroke dementia or Parkinson’s dementia |
| • Is Cedar House due to close – but it isn’t mentioned |
| • Carers and the people they care for need help and advice when going into residential care, also finance issues |
| • Nothing about NHS funded Continuing Care – either in the home setting or in a Nursing Home or how to support Carers |
| • No mention of End of Life Care for both service user and Carers or the NHS Surrey County Council funding arrangements |

Table 10: carers – (continued)

| Carers |
|--|
| <ul style="list-style-type: none"> • There is some disappointment that this is a limited strategy, with some issues barely addressed, despite all the good work that has gone into it concerns raised that the strategy is over reliant on the willingness of carers to provide care figures do not reflect that 70% of carers are of working age |
| <ul style="list-style-type: none"> • South West Carers Group would like to have someone to talk to the group about the implementation plans at a future meeting |
| <ul style="list-style-type: none"> • Carers can find themselves very isolated, often elderly and do that have their own transport |
| <ul style="list-style-type: none"> • Carers tried to set up a support group to circulate relevant information but were prevented by Data Protection Act |
| <ul style="list-style-type: none"> • More information needed on Dementia Advisors: will roles only support those with dementia expertise? If they have expertise in other mental illnesses, job titles should change |

Table II: general comments about the strategy

| General comments about the strategy |
|---|
| • No mention of people with dementia and physical disabilities |
| • Lack of coordination and communication by those in authority |
| • Future problems of recruitment, retention and training of staff |
| • “We fully endorse the concept of choice and agree that supporting people to remain in the community. We would welcome participation in discussing service proposals” (Surrey Care Association) |
| • Anxiety that this strategy may be aspirational rather than deliverable, especially in the current financial climate |
| • Nothing about Parkinson’s orgs and how they support people |
| • Professionals do not listen to us |
| • I do think that the strategy is very clear about how the pathway and services will proceed |
| • Little recognition of the need to work with Independent Sector |
| • Jigsaw diagram unhelpful in explaining the connectivity between services |
| • Best Practice unit, is this an additional complication in pathway |
| • Need more detail on investment disinvestment issue |
| • Phasing unrealistic with everything planned in year one |
| • Lacking stakeholder commitment/engagement – “We believe that the plans set out in your document will be generally welcomed but have concerns that you could be raising expectations that cannot be met” |
| • Concern was raised that the strategy lumped both mental illness and organic dementia together |
| • We are concerned how you will address the tension between current inequitable services whilst trying to deliver new or reorganised services |

Summary



Although the questionnaire responses only numbered 135, overall there was an immense amount of feedback, both individually and by groups. There were 361 individual responses at the National Dementia Summit and many highly detailed direct responses from a further 14 organisations and individuals.

Do you agree with the priorities we have chosen for Surrey?

Overall, there was almost universal agreement from the 135 responses to the key proposals (see Figure 1). The only significant concerns being around intermediate care in general hospitals and improving inpatient care.

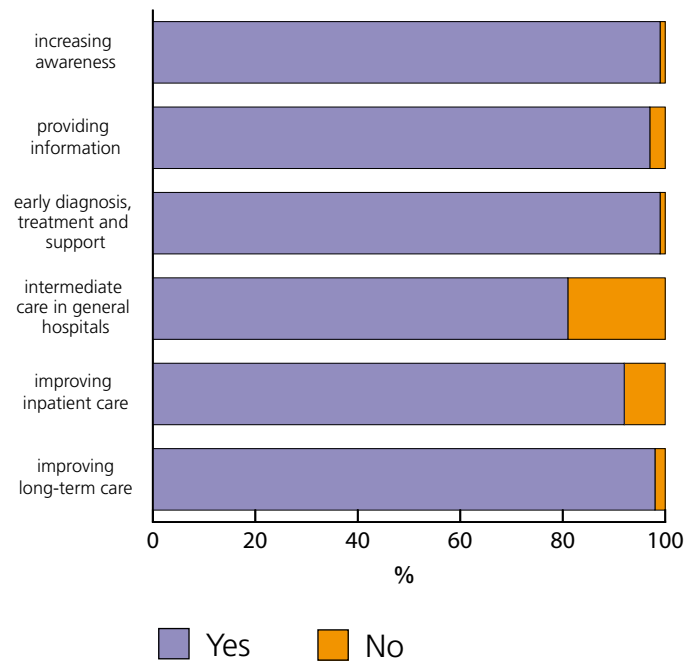


Figure 1: do you agree with the priorities we have chosen for Surrey?

There were a few negative comments about the strategy all along similar lines:

“There is some disappointment that this is a limited strategy, with some issues barely addressed, despite all the good work that has gone into it.”

In the main comments and concerns focussed around three main topics:

Carers

The bulk of comment was from carers and addressed the general lack of support and advice available, especially in times of acute need. The element of training occurred repeatedly and it was felt that better training would not only enable carers to cope better but to also pre-empt many difficult situations. Networking was a resource people wished they had more access to and would also help overcome their feelings of isolation. Day care provision and finances were a worry also and again greater provision and funding for these resources vital.

Care Pathways

The main responses focussed around greater integration of the lines of information, support and communication between individual care agencies and care workers. It was felt that this would facilitate better, quicker and easier access to care provision. There was also mention that while many services were excellent there weren't enough of them and they were not equitable across Surrey. Mention was also given to GPs and that it was felt that not all were sympathetic or had time to those suffering from Mental Health issues and their carers.

Funding

It was felt that while the strategy overall was excellent and workable, that there would not be enough resources to complete all the proposed initiatives. There was also practical concerns that the initiatives would not be able to be rolled out all at once due to staffing and organisational issues. Many commented on the uncertainty of the current financial situation and wondered whether the strategy was feasible in this uncertain fiscal climate.

Special needs

Although the initial strategy was initially going to exclude people with Learning Disabilities who have developed dementia, it has been expressed that there is a wish to incorporate this into the main strategy. This has been accentuated throughout by the particular concerns raised towards not only people with Learning Disabilities but also those with Early Onset Dementia.

This independent summary has highlighted the most frequent recurring messages. It does not seek to make recommendations nor to suggest that the feedback is representative of all residents and stakeholders. The consultation feedback is one of many pieces of evidence that NHS Surrey and Surrey County Council will consider when making decisions about next steps.

A complete list of all 54 Outreach Events:

SW GP LEC – Farnham Hospital
NW LEC – Woking Hospital
Surrey LINK AGM
Banstead Horseshoe Community Centre – OP Drop-in
Woodhatch Community Centre – Reigate Drop-in
Surrey Dementia Summit – Sandown Park
Alzheimer’s Society – open evening
SE Coast Ambulance Service Event
Alz Cafe Drop in – Claygate Centre
Elmbridge Civic Centre
Royal Surrey Hospital
Spelthorne Forum for Older People
Heart of Walton Shopping Centre
Elmbridge Forum for Older People
SW Carers Strategy group
Reigate and Banstead Local Strategic Partnership
Sheerwater Summer Festival
Carers Support (Guildford) committee meeting
Runnymede Older People Forum
SW Older People’s Reference Group
Spelthorne Fun day
NW Alzheimer’s Carers Group
Moorcroft Community Centre – Woking
Manor Farm Centre – Egham
Woking Community Hospital
The Vyne Community Centre – Woking
The Orchard Centre – Chertsey
Surrey Care Link

St Mary’s Community Centre – Byfleet
Eileen Tozer Centre – Addlestone
Parkview Centre for the Community – Sheerwater
Woodham and New Haw Centre
Carers forum for Dementia Strategy – Woking
SBPT Focus meeting – Addlestone
Ashley Centre – Epsom
Elmsleigh Centre – Staines
Spelthorne Together: Health and Well-Being group
Surrey Care Association – Older Peoples network meeting
Carers forum for Dementia Strategy – Reigate
Surrey Care Association – Domiciliary Care Network meeting
SW GP LEC – Farnham Hospital
NW LEC – Woking Hospital
Epsom and St Helier Trust – Annual Public Meeting
SW Carers Strategy, Ian Goodchild Centre – Camberley
North Place – Guildford
Spelthorne Together assembly – Kempton Park
Alzheimer’s Society Mole Valley carers group
Sunrise Care Home – Bagshot
Equality and Diversity Forum – Astolat
Woking Mosque
East Surrey Hospital
Park Barn Centre – Guildford
Shawfield Centre – Ash
NW Carers Strategy Forum – Woking