

**Kent County Council**

# Older Persons Engagement

Feedback June 2017

Dementia Friendly Communities Project Team



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## Your Life Your Wellbeing

Kent County Council we are working towards the ethos of our residents 'having a life, not just a service'. This is something we were keen to discuss with the people across Kent to gain an understanding of what is important to them and to get a good sense of what the people of Kent need in order to feel safe and live happy, meaningful and fulfilled lives.

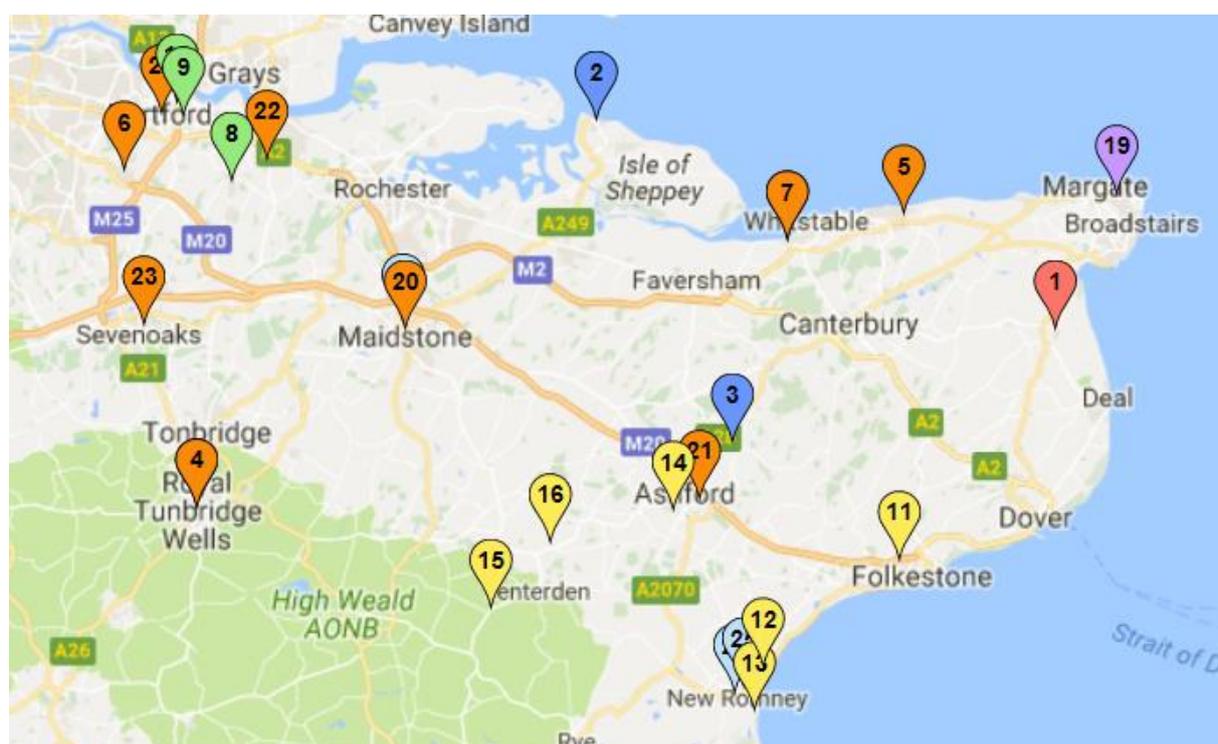
## Thank You

We want to ensure that all of the organisations and groups we have engaged with during this process are aware that their support has been invaluable; the process has been far more emotive and challenging than any of us envisaged.

It became clear during this work that many people we spoke to have seen us as a willing listening ear, someone 'new' and disconnected to any services they may be engaged with and this has, on a number of occasions, led to disclosures of issues or circumstances which may otherwise have remained hidden. We must stress that this is not a reflection on any of the services we were engaged with it was rather a by-product of having someone new to talk to.

On occasion our team took action and sought support from staff members and others in order to further support the individuals needs and we are extremely grateful for the support that the hosting organisations have provided.

## Locations of Engagement



## **Who We Have Spoken With**

We have spoken to over 200 people over 55 years of age, we attempted to reach a wide range of Kent's older residents and have spoken with people from a range of social backgrounds and with a range of varying personal situations. This has ranged from the very active retired people who are not in receipt of any social care services to those who are considered vulnerable and frail, living with multiple long term conditions and receiving support from multiple services.

## **Categorisation**

For ease we have loosely categorised those we spoke to into three groups. Although these could easily be split further

- Active Retired
- Family Carer
- Receiving Services (This could be voluntary sector and / or social care)

We found that categorising people further according to age was not suitable as the circumstances were not necessarily age related.

People also crossed over groups, e.g. those caring could also be receiving services themselves so this is why they have been 'loosely' categorised.

## **Methods**

Based on the principles of grounded theory we used an iterative approach which allowed us to start with a number of open questions. We used a variety of methods including group discussions, one to one visits to people in their own home using guided conversations plus a questionnaire for family carers. We have themed the responses and have continued to both review and test these themes in subsequent conversations with people.

## **What We Discussed**

As a part of our engagement we spoke to people about their daily activities, what they enjoyed doing and what was truly important to them. We also asked how they received information and how they felt they should receive advice and guidance.



was also the consideration that they spent a considerable amount of their time finding activities which could be done with their 'cared for' such as going for lunch or on short trips out. Those who lived with their 'cared for' often spoke more about what they did for their 'cared for' rather than what they 'do' for themselves. This implies that a majority of what they do is provide 'care'.

## Quotes

*"It's too much fuss and bother to get up and out early, its stressful even getting ready for 10:30am, sometimes the stress of that makes going out not worth it".*

*"I don't know what day it is half the time, there's nothing different from one day to the other"*

*"Three meals a day and being alone inside four walls for most of it sounds like prison but it's what they call 'care'"*

*"My body is old but my mind is not, it's really frustrating"*

## What People Miss...

A word cloud of activities and interests people miss. The words are arranged in a roughly circular pattern, with 'sports activities' and 'working' being the largest. Other prominent words include 'cinema or theatre', 'dancing', 'getting out the house', 'being independent', 'garden', 'arts & crafts', 'family and friends', 'shopping', 'walking', 'driving', 'companionship', and 'baking & cooking'. Smaller words include 'exercise club', 'holidays', 'day trips', 'volunteering', 'having a break', 'long walks', 'watching sports', 'learning new skills', 'support with computers', 'school children visits', 'eating out', 'DIY', 'being 'useful'', and 'doing my own cleaning'.

- With this the 'active retired' many people talked to us about future aims and aspirations rather than any difficulties. A few people mentioned that they have adapted the way they do things or have changed the intensity of an activity rather than stopping it.
- When speaking to the group receiving services there were in-depth conversations about what people miss. Missing various forms of physical activity was the most common answer with people telling us that they miss dancing, walking, cycling and bowls, mainly due to their mobility. People also told us that they missed 'going out' 'going on trips' and also 'gardening' this was often attributed to a lack of mobility and confidence, or a lack of someone to accompany them, as were social and leisure activities such as going for lunch, theatre, cinema and club outings. Another common theme we found in answer to this question was around the subjects of feeling independent, valued or useful, with many people talking about missing work, cooking, driving and doing their own cleaning and also their own personal care, this was often followed by being told that the person does not want to be a burden on anyone.
- Those residents which fell into the family carers group had many of the same issues as those receiving services yet for different reasons, quite often it was not their own mobility or confidence issues which was stopping them from participating in activities but instead they were unable to participate due to caring responsibilities, time and motivation.

## **Barriers**

When speaking about barriers to people doing what they would like to do, a lot of people spoke about:

- Lack of confidence
- Lack of physical ability
- Shame or embarrassment due to various 'conditions'
- Effort needed and energy levels outweigh gain
- No one to go with/take me
- No way of getting there
- Not able to use public transport/lack of accessible public transport/no buses – confidence to get on and off a bus on their own.
- Quality of the paths/pavements are poor and concerns about falling
- The feeling of 'outside' not being safe

- No shops locally and the shops they would like to go to aren't accessible to them
- Accessible shops/restaurants – narrow doorways

## Quotes

Shopping – “You will learn to cherish it when it's the only time you go out”

“When I do go out, it's just a different place, lots of people and noise but people don't really talk to me, or I don't hear them ..... but its company”

“I don't go out that much because I am frightened of falling, the pavements around where I live are dreadful, and so I tend to stay at home unless I can walk with someone”

## What People Think is ‘Most Important...’



- People across the groups were very similar in their answers to this question however they found it difficult to explain ‘why’. Most commonly people answered that family was the most important thing to them, very closely followed by

companionship, friends and other forms of social interaction. There was a clear distinction between company and companionship in many of the conversations, with people explaining that sometimes they feel lonely even with people around them. A person's faith, remaining active, stimulated and keeping busy was also high on people's lists.

- For those in the active retired group there were a lot of discussions about maintaining independence and lifestyles, having options and being able to get out and meet people as and when they choose to.
- The group with people receiving services also had a number of conversations around the aspects of feeling valued and retaining their dignity.
- With the family carers group the conversations centred on the 'cared for' persons quality of life, respite and trying to find some time for themselves.
- Carers are very split – some agreeing with those using services that shorter periods are best – others wanting longer periods of activities away from home to give greater respite

## Quotes

*"I just want to have a proper talk to people"*

*"People look forward to the company of a carer (paid care)"*

*"I used to go to the pub up the road for lunch for years, my wife and I enjoyed that. Now I am on my own and cannot walk well. I can't go there anymore".*

*"I can't take my dogs out for a walk, they just have to manage with the garden and that upsets me a bit, I don't trust anyone else to take them out"*

*"My village doesn't have a lot of shops, I can't get safety pins anywhere here or buy any clothes. I can't get on a bus on my own to get some"*

*"I'd like to see the sea, I love the sea but I can't get there"*

*"I've been to the Day Centre, but it's boring. I just sit there and read the paper, I can do that at home. There aren't many other men to chat with"*

## How People Receive 'Information'



- A large amount of the active retired group felt that they were competent with IT equipment but it would depend on the subject matter. People we spoke to, despite having access to a computer, did not necessarily feel that it was the best place to look for or receive information. Many people distrusted information found 'online' while others were very adamant that they would prefer a person to an anonymous person on the internet. Most often it was seen to be a mechanism to locate appropriate people to talk to. Online forms and services were often seen to be confusing and people often gave up and looked for a person.
- A majority of those receiving services told us that they did not have access to computers and had no interest in learning, a few had hand held tablet devices which were used for games or books.
- The family carers group often had access to IT equipment however they were very similar to the active retired in their usage.
- Outside of the internet, information about local events and activities was generally found from local newspapers, information boards and word of mouth. Advice and guidance was generally sought from friends and family, local GP's, faith groups and local charities such as Age UK and Age Concern.

## Quotes

*“Everything is on the ‘internet’ some of us don’t have a computer or want one.”*

*“I can look things up on google but if it’s something important I would want to talk to a person, you can’t always trust what you find out on google.”*

*“We have a noticeboard here but there is very little on it and it’s not in a good place, by the bus stop would be good!”*

*“I hear most things by word of mouth and I like it that way.”*

## Coping with Loneliness...

A word cloud of coping strategies for loneliness. The words are arranged in a roughly circular pattern. The largest word is 'television' in red. Other prominent words include 'nothing you can do' (in blue and purple), 'phonecalls' (in purple), 'stay positive' (in red), 'watch out window' (in red), 'radio' (in red), 'photographs' (in purple), 'speak to people' (in blue), 'reading' (in red), 'keep brain active' (in orange), and 'talk to care staff' (in purple).

We asked people about ‘Loneliness’ and how they managed or coped with feeling lonely.

- Those in the ‘active retired’ group rarely stated that they felt lonely, although on occasion we were informed that of an evening when they may be home alone they sometimes considered that they may be lonely but they had strategies in place such as the internet or hobbies which helped.
- Loneliness was far more an issue with those ‘receiving services’ and ‘family carers’ particularly during evenings and night times

- Those receiving services seemed more likely to resort to watching television and doing solo activities to keep the mind occupied such as reading and puzzles. We were told many times that the loneliness was due to mobility issues and the effort and energy it would take to arrange to go out, therefore on balance they remained home. There were also concerns around safety outside the home, both perceived threats and environmental concerns.
- With the 'family carers' it was more loneliness due to lack of ability to socialise, often due to time constraints.

## **Loneliness Case Studies**

Mavis is 76 and married to Dave 73 who is receiving regular treatment at hospital 3 days per week - *"when Dave is at the hospital for 3 days a week I get really lonely"*. They both hold freedom bus passes and this enables them to travel across the county each week and they continue to explore a varied social life together.

*"Monday, Wednesday, Thursday, Friday, Saturday and Sunday are like any day of the week just looking at the four walls of the house with nothing to do, Tuesday is the Befriending Club so I do look forward to that"*.

Bert aged 89 is living at home on his own and finds life "boring to the extreme".

*"I feel lonely, particularly in the summer, the days go on forever, at least when it's winter it gets dark early and I can go to bed"*.

Voice of a carer *"We go out for lunch as it's easier, it takes up most of my day preparing, cooking and clearing up after meals and takes time away from my caring for my wife, eating out is a break for me"*.

Janet was alone having lost her husband a few years earlier and attended the day centre three times per week. *"I only eat enough to keep me alive"* Janet lives alone and does receive some visits by her family but spends much of her time on her own with only the TV for company.

*"In the evenings I have the television on sometimes but there's nothing good on, I can't hear it most of the time anyway!"*

## **We also asked people, in hindsight is there anything you would do differently or advice you would give those getting older?**

*"Be as naughty as you can get away with!"*

*"Don't follow your children"*

*"Think about where you live, realistically is it somewhere good to be if things get bad"*.

*“Invest in a good pension”.*

*“Do as much as you can while you can”.*

*“Put more money away”.*

*“Think about the future, what could happen and get advice”.*

*“Spend it while you can and enjoy every minute of it”.*

*“Get fit and keep fit”.*

## **Case Studies**

### **Margaret's Story**

Margaret has been coming to a day centre twice a week for almost two years, when we spoke she was very emotional and anxious and explained that she was struggling to deal with the loss of her husband. Margaret cries at home a lot, she has bouts of anxiety and depression and hasn't told anyone. She misses her husband, doesn't know where to turn and feels lost.

Margaret started to see people who were not there and to see doors move on their own, she told us “I need help” and seemed surprised when told that there really are people out there who can help her. We asked Margaret if she would like someone to talk to about her worries and perhaps have some bereavement counselling, she said that she would love that as she doesn't want to bother her family who work. She also told me she was really quite unhappy where she lived as she didn't have any friends there.

With Margaret's permission this was related to the Centre Manager who immediately arranged for a Support Worker to intervene.

### **David and Sarah's Story**

David and Sarah attend a Lunch Club most days, they are in their 80's. Sarah has lost the use of one arm due to a stroke several years ago and relies on a mobility scooter to get around. David is in reasonably good health and is her full time carer.

The lunch club makes their dinner and that makes life easier for them and this also gets them out to talk to others. David and Sarah manage on their own and advised that they don't receive any benefits or any carers support services. Sarah had

previously been in receipt of Domiciliary Care but in David's words "they were more of a hindrance than a help".

David said that the one thing he would like to be able to do with his life is to have a break, just some time here and there to potter in the shed, or do some DIY. He really misses his work. Parking near his home address was also a big concern. The role of a Care Navigator was explained to the couple, as was information about Carers Support

They were very surprised that there was a role in the Community such as the Care Navigator and would be very happy to meet with her.

### **Lois and Clark's Story**

Lois is 84 and married to Clark aged 87.

They live at home with their daughter who provides a little support to them. Lois and Clark have led varied and active lives and have fostered in excess of 30 children throughout their lives. They spent much of their early years being active and participating in badminton and bowls, however following the diagnosis that Clark has Parkinson's this has significantly impacted in what activities are available to them.

They have attempted to keep their links with bowls however have been advised that Clark would not be welcome with his wheelchair. Lois would love to be part of a choir but struggles to find anything local and currently the only activity that the pair participates in is the weekly befriending group.

### **Lisa's Story**

Lisa is 57 and now lives with her daughter in a specially designed flat suitable for her use of her wheelchair due to her physical disability. This move has resulted in her being away from her friends who cannot visit her. She has recently had a bereavement and is due for hospital treatment. There is a history of depression and she feels very isolated and is concerned about her weight gain. Social Services have provided care once a day to assist in getting up, however the only option provided to her in regards to social engagement is referring her to a befriending service. Lisa has a befriender visit; this service is very much valued and appreciated. She looks forward to going to hospital appointments as it gets her out of the house. She misses work and being 'busy' and feels very low emotionally and feels she has no value, she would like to do anything to keep her occupied.

## Observations and Themes

Although we did not ask people about specific services it was clear that people valued and were very grateful for the services that they received. Throughout our conversations however we found that many people mentioned a desire to not be a burden on anyone, also the belief that they were lucky to have the services that they did, so “should not grumble”.

This does not detract from the services they are in receipt of, but in some cases may explain why as ‘outsiders’ our team received information and queries, that may otherwise not have surfaced.

Just because people are linked into a ‘service’ doesn’t mean **all** of their needs are being identified/ addressed.

There were a number of missed opportunities to better aid residents by referring on to other organisations or departments, or to look for ‘community’ or ‘outside the box’ solutions to meet that individuals needs or outcomes.

### Themes: General

Company but not always ‘conversation’.

Environment makes a big difference to the conversation.

The passion from the carers that as soon as they are financially assessed and do not qualify for support it ends, they are then left on their own to sort everything out and pay for it.

The difference between those more elderly and the younger people we spoke to ... The older people seemed to ‘accept’ what they were given, this often applied to those carers and those engaged in services. There was almost a feeling of ‘accept and make do’ – ‘don’t rock the boat’ or ‘bite the hand that feeds you’, ‘be grateful for what you have’ and ‘things could be worse’....

The younger people had more ‘expectations’ and again many of the younger active retired and younger carers had greater expectations of what life should consist of

This is probably reflective of the times, our children may have even greater expectations due to the more ‘throw away’ culture.

### Themes: Housing schemes

Most did not experience any feelings of loneliness as there was always someone available to talk to.

Activities were available most evenings and afternoons but they were very typical types such as bingo and quiz nights.

Residents spoken to say that they were happier living in the scheme and it was the right choice for them.

Residents did not want to be a burden on their children and living in the scheme provided them with the security of being in a safe environment.

Residents were able to participate in minor gardening activities throughout the grounds of the scheme.

Not always a clear understanding from family in regards to expectations from extra-care, care homes and nursing homes.

Residents that lacked confidence with their mobility expressed that they would have appreciated some support to visit other local areas with the support of staff. Resources were not available to facilitate this request.

Activities were not available off site unless residents could make their own way to and from the venue.

### **Themes: Carers**

A large amount of people we spoke to are, or have been family carers, yet did not always recognise them as such.

There were people who would be classed as a family carer for their spouse.

Others, although classed as an 'older person' themselves, were carers to parents and in one case both daughter and mother were in the same extra care centre with the mother being elderly and frail and the daughter with disabilities.

There was quite a difference we found across the age groups of those in a caring role, an observation which we all made was that the more elderly persons looking after a spouse were more of a mind that they did not want to burden the rest of the family, a strong feeling of "for better and for worse" and a feeling of gratitude for anything put in place to support them, very much a feeling of 'acceptance' but often coming across exhausted and tired themselves.

When speaking to those younger persons who had concerns about parents it was a very different feel to the conversations, quite often there were many other demands on the individuals time and far greater expectations of what should be provided, quite often they were very unhappy about the provision of services and more often than not great dissatisfaction around financial assessments and provision of information. A common trend was statements around once it was decided that they would have to fund their own care there was no help or direction.

## **Barriers Specific to Carers:**

When speaking about barriers to people doing what they would like to do there were a number of issues quite specific to carers.

- Lack of physical ability to 'enable' their cared for, a number of carers have their own health conditions to take into account.
- Demands on time, quite often an individual can be caring for multiple persons at once.
- Finance and understanding entitlement, often when a decision is made in regards the 'cared for' it is not clear that the carer has their own entitlement.
- Shame or embarrassment due to various 'conditions' such as behaviour and incontinence etc.
- Confidence, or lack thereof, in presenting a good front while 'in company' some older people we spoke to felt they needed to show that they can cope. in some cases there was a fear that should they admit a weakness that their cared for would be put into a residential care home.
- Effort needed and energy levels needed to achieve a goal can be too high a price to pay.
- No way of getting there with their cared for, working around routine and use of public transport public transport/ lack of accessible public transport. Time public transport consumes.
- The feeling of 'outside' not being safe for the 'cared for'. Feeling safe was high on the list of requirements for their cared for.
- Accessible shops/restaurants, narrow doorways.
- Toilets seemed a barrier on its own particularly with dementia or similar conditions. Male and Female toilets are fine if the cared for needs to make use of them as the carer can wait outside. Should the carer need to make use of the toilets then there are concerns about leaving the cared for.

## **Themes: Intergenerational**

There were a number of conversations about the different generations with many people talking about the fact that they enjoyed having younger people visit, this was usually more specific to primary school children

A number mentioned young family members and that they enjoyed spending time with their younger relatives.

Others mentioned that they found themselves excluded from the younger people, either through their choice or others. Some were living in special housing or a complex where they were segregated from the wider population and had little understanding or interaction with the younger generation.

Some people living within the wider community spoke about feeling unsafe or intimidated by groups of older children and a fear that they may be harmed by accident or design, so in many cases avoided going out when children were not in school.

## **Recommendations**

That these findings, themes and case studies influence how we design services which support older people in Kent now and in the future. From the information which we gained throughout this engagement we would also recommend that the contents of this report be shared with the following departments organisations and key stakeholders.

- Kent County Council
- Local Voluntary Organisations
- NHS and Health
- Local Councils
- Emergency services
- Community Safety
- Local Business
- Young People/Schools

## Appendix 1 – Who we spoke to

Place	Postcode	Number of people engaged with
Age Concern Sandwich	CT13 9AP	15
Age UK Sheppey	ME12 2PF	11
Wye Village Hall	TN25 5ET	8
Age UK Tunbridge Wells	TN1 1LU	21
Age UK Herne Bay	CT6 6LE	22
White Oak Court extra care	BR8 7WF	8
Whitstable coffee morning (Age UK)	CT5 4AX	9
Carers Café Wellfield	DA3 7EG	8
Befriended	DA2	1
Befriended	DA1	1
Age UK Folkestone	CT19 4NS	12
Befriended	TN29	1
Befriended	TN28	1
Age UK Ashford	TN23 5RF	7
Befriended	TN17	1
Befriended	TN26	1
Age UK Tunbridge Wells (dementia group)	TN1 1LU	15
Whitstable church older person coffee morning	CT5 4AX	12
Thanet resource centre - lunch club then COGs Club	CT9 3TN	2
Heart of Flavour, Maidstone Older person lunch group	ME14 1BA	2
Chamberlain manor Ashford - Extra care	TN24 8BF	8
Istead rise surgery older person befriending group	DA13 9LA	3
Dartford Library /befriending group	DA1 1EU	4
Imago Group Tunbridge Wells		7
Romney Marsh day centre	TN28 8JB	15
Maidstone Group	ME14 1XX	9