



## **Fife Dementia Strategy Review**

### **Online and Paper Consultation Report**

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[21 March 2022]



## Contents

<b>1. Introduction and Methodology</b> .....	3
<b>2 Consultation Collated Responses</b> .....	4
<b>2.1 About You</b> .....	4
<b>2.2 Your Experience of Dementia Services and Support</b> .....	6
<b>2.3 Diagnosing Dementia</b> .....	9
<b>2.4 Immediate/Initial Post Diagnostic Support</b> .....	11
<b>2.6 Future and Emergency Planning and End of Life Planning</b> .....	17
<b>2.7 Improvement Priorities for Fife’s New Dementia Strategy</b> .....	19
<b>2.8 Your Priorities for Improvement</b> .....	21
<b>3. Conclusion</b> .....	21
<b>Appendix 1</b> .....	23
<b>Appendix 2</b> .....	48



## 1. Introduction and Methodology

Fife Health and Social Care Partnership have completed the collection of feedback for online and paper consultations as part of the overall Dementia Strategy Review. Respondents were those who live with dementia, those who support someone living with dementia including paid and unpaid carers.

Fife Health and Social Care Partnership launched the online and paper consultation on 09 November 2021 through to the closing date of 31 January 2022. In total 67 responses were submitted – 46 online and 21 paper. 2 late paper response were received - it should be noted that these responses are not included in the analytics displayed in this report. It can be confirmed that the themes from the late responses were broadly in line with the formal responses received before the closing date. One late request to have a in person meeting was carried out after the consultation closed. Points of discussion were recorded and included within the feedback findings. It is recognised that there is a high likelihood that some of the on-line responses were received from individuals who attended participation and engagement workshops on "Living Well With Dementia".

The Public Engagement Team used MS Forms as the online consultation tool. No questions were made mandatory. The link to the online form was shared widely with Stakeholders for distribution; shared on social media platforms namely: Facebook and Twitter and from those posts the link was again shared by various community groups on their social media platforms. The online consultation was also translated into BSL and the link for this was incorporated into social media posts.

The online consultation was produced in paper format with 1000 copies produced for distribution. Paper consultations were distributed to every care home in Fife, Day Services and to the Dementia Initiative in Fife. Social media posts included information that the consultation was available in paper format if requested by emailing the Public Engagement Team. The paper consultations were then inputted into a back-office MS Form that replicated the paper format. It should be noted here that due to printing anomalies the paper version displayed a slightly different format than the online consultation on three questions therefore a back-office MS Form was created for inputting paper returns for analysing purposes for those three questions. This is recorded in the findings report below for the purposes of transparency and openness.

Feedback within this report has been collected via both methods described above.

As a public reference group, the existing group STAND (Striving Towards A New Day) which is a peer support group for those with early onset dementia was used. This group reviewed our online/paper consultation for suitability and sense test purposes. Fife's People Panel were also included in sense testing the consultation.



## 2 Consultation Collated Responses





### 2.1 About You

This section was aimed at collecting data that would help to understand the demographic of who was completing the consultation. Within this section participants were also asked if they were aware of Fife Health and Social Care Partnership 's current Dementia Strategy. Data from responses have been analysed below:

Total number of responses to this section: **64**

#### Percentage breakdown:

##### 1. Are you






 Living with dementia	6
 Providing unpaid care to one ...	39
 A paid professional in dement...	14
 Volunteering to support peopl...	3

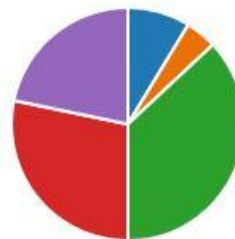


#### Q2 Online Response Percentage Results : 46 Responses

2. At what stage of the illness would you say your dementia [or the dementia of the person you are caring for] has progressed to?

[More Details](#)

 No illness or symptoms	4
 Pre-diagnosis with some sym...	2
 Mild illness	17
 Severe illness	13
 Advanced or end stage illness	10

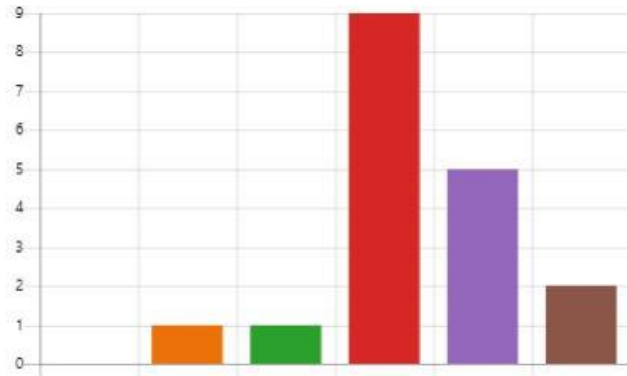


#### Q2 Paper Response Percentage Results (still to update with paper data)



2. At what stage of the illness would you say your dementia [or the dementia of the person you are caring for] has progressed to?

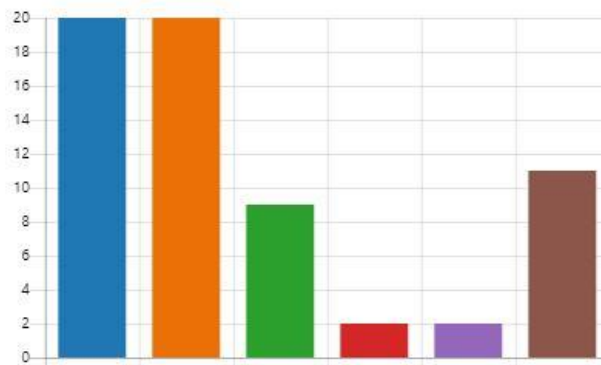
<span style="color: blue;">●</span> No illness or symptoms	0
<span style="color: orange;">●</span> Pre-diagnosis with some sym...	1
<span style="color: green;">●</span> Mild illness	1
<span style="color: red;">●</span> Moderate illness	9
<span style="color: purple;">●</span> Severe illness	5
<span style="color: brown;">●</span> Advanced or end stage illness	2



3. If you are living with dementia or caring for someone with dementia, how long ago did you (they) receive the diagnosis?

[More Details](#)

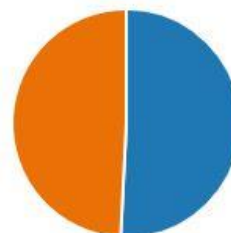
<span style="color: blue;">●</span> In the last year	20
<span style="color: orange;">●</span> 2 to 4 years	20
<span style="color: green;">●</span> 5 to 7 years	9
<span style="color: red;">●</span> 8 to 10 years	2
<span style="color: purple;">●</span> More than 10 years	2
<span style="color: brown;">●</span> Uncertain/Not sure	11



4. Do you (or person living with dementia you caring for) also live with another life limiting or chronic illness?

[More Details](#)

<span style="color: blue;">●</span> Yes	32
<span style="color: orange;">●</span> No / Nothing diagnosed	31

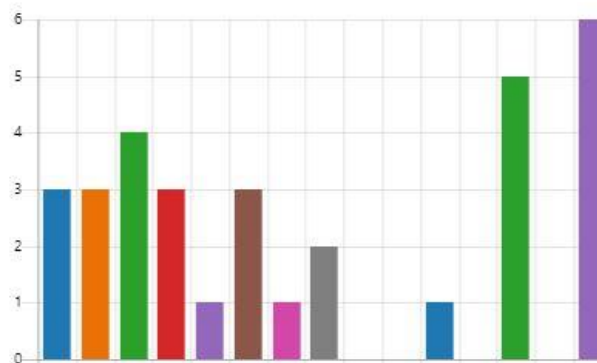




5. If you answered yes to the question above, please specify what the life limiting or chronic illness is?

[More Details](#)

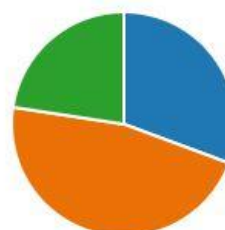
● Hypertension (high blood pre...	3
● Depression	3
● Coronary heart disease (CHD)	4
● Stroke or transient ischaemic ...	3
● Diabetes	1
● Parkinsonism	3
● Epilepsy	1
● Cancer	2
● Weight loss or eating disorder	0
● Incontinence	0
● Chronic obstructive pulmonar...	1
● Asthma	0
● Physical disability	5
● Sensory loss	0
● Other	6



6. Fife Health and Social Care Partnership already has a dementia strategy. Please rate your awareness of it.

[More Details](#)

● Do not know anything about it	19
● I am aware there is a strategy ...	29
● I am aware of the details in th...	14



## 2.2 Your Experience of Dementia Services and Support

Total number of responses to this section: **63**

In this section respondents were asked to answer questions to record their views of the **general information and awareness of dementia**. Data from responses has been analysed below.

On a scale of 1 to 5 with 1 being poor and 5 being excellent respondents were asked to rate their experience of the general information and awareness they have received about dementia. The average score was **3.16**.



When asked what aspects of **general information** and awareness work well **50** individuals responded giving a mixed response. Many identified that having information on how to support someone with dementia, information available on diagnosis, benefits, and the ability to access online documentation worked well. It was noted by some respondents that information from community support groups/organisations was excellent.

*What to expect re behaviour /issues that the dementia sufferer may experience and the best way to deal with the individual*

*I am lucky as I have been working with Ruth McCabe (Fife Council Dementia Friendly Initiative) raising awareness in Fife since diagnosis. General awareness and information has been excellent*

*Initial information available upon diagnosis was excellent, particularly the visit from Dementia Support Worker during that first year*

*Having information/literature leaflets & resources on- line*

*Advice about daily living entitlements to retain independence e.g Attendance Allowance, Blue Badge and tech gadgets such a pill dispenser*

*The dementia book that my dad received on receiving his diagnosis was very user friendly and informative*

*My mum and myself have been attending the STAND good life course which has helped my family immensely with how to cope with the disease and to who to contact for certain things and how to claim for the appropriate benefits etc*

*The basic training videos I have seen through my work and personal experience with relatives*

did not work well, with some stating that they have received little to no information at all. Comments received highlighted that information regarding the progression of dementia could be improved along with other clinicians being more dementia aware.

*I had to search for information or word of mouth*

*There wasn't any information on dementia, the only awareness I know about is Alzheimer's Scotland and walk for dementia.*



*An awareness that good support from Care services is ridiculously difficult to obtain and that you have to battle to obtain an assessment for SDS*

*Advice about the progression of the illness. For example, my mum has Parkinson's and we were not directed to the possibility that her hallucinations and confusion could be a sign of dementia*

*None as I've received nothing since being told dad has Parkinson's dementia in July after his assessment which as his POA, carer was not invited too.*

When asked how **general information and awareness** could be improved **52** individuals responded. They identified improvements again giving mixed responses. These included improvements could be made by having concise information in one accessible place and being directed to this information at the point of diagnosis (or near to) would be of great benefit. It was also stated that being signposted to community support/peer groups would be an improvement.

*I think setting up group chats may work well for both the person living with Dementia and the care giver.*

*A booklet given to the carer with up-to-date information with regard to caring for a Dementia sufferer.*

*People being newly diagnosed would benefit from being directed at point of diagnosis to local peer support groups who could then provide information, answer any questions about how to live well with dementia.....*

*As a worker, I believe people know the strategy is there but they wouldn't necessarily seek it out or make reference to it. Perhaps email bulletins reminding us of the main information would be helpful and to make it more relevant to us*

*Provide all information in one accessible place. Instead my sister and I have had to learn about services, aids and information about the condition from a wide variety of sources*

*The first time my Mum had a visit we were given some books and leaflets to read. Mum never read them and is still in denial. I have read all the info and whilst most of it is informative it is difficult for me to reach out for help and further information..... I would say a proactive approach from the care teams would massively benefit sufferers and carers alike*





## 2.3 Diagnosing Dementia

Total number of responses to this section: **55**

In this section respondents were asked about their views of their experience of **diagnosing dementia**. Data from responses has been analysed below.

On a scale of 1 to 5 with 1 being poor and 5 being excellent respondents were asked to rate their experience of the **diagnosis of dementia**. The average score was **2.85**.

When asked what aspects of the **diagnosis process worked well** for them **45** people responded. It was highlighted that having GPs who are dementia aware and listen to the family works well. Good communication, teams that linked well and positive attitudes towards dementia were key in the diagnosis process being a positive experience.

*I am one of the lucky ones. I had a GP who was on the ball and could see that something wasn't quite right. I also had an excellent diagnostics team at Victoria Hospital who were with me every step of the way (including our specialist nurse).*

*The GP listened to our family and took the concerns seriously and acted quickly. The process was well co-ordinated, the district nurse, CPN and Consultant all communicated well.*

*Clear communication and seeing teams link and communicate well*

*The mental health nurse kept us informed of what was happening*

*The doctor was quick at making a home visit the week after my dad's visit to his GP surgery due to him being aggressive when Practice Nurse mentioned him going to memory clinic appointment. The same doctor was really good at putting my dad at ease and explaining all*

*Care from the Psychiatrist at Whyteman's Brae (Dr. Last) was excellent. Caring, compassionate, considerate - and explained things very well. Provided invaluable support on a number of*

*Attitudes towards dementia were very positive*



Other respondents indicated that their experience of the **diagnosis process did not work well** indicating that other services were reluctant to support diagnosis and that contact from professionals could be improved.

*The 'support' offered in connection with my mum's diagnosis was shockingly poor. It seemed that various specialist services particularly Parkinsons support took the approach of 'this is the responsibility of another service'*

*There has been no formal diagnosis from my mums GP, little contact and to be honest I've lost faith in her GP and health practice*

When asked how the **diagnosis process for dementia could be improved**, 50 responses were received. Respondents commented that waiting times need to be reduced for diagnosis. Again, comments were noted that GPs should be aware of dementia/early onset dementia and should listen to families more. It was also noted that having a specialist from the point of diagnosis through to support would be a benefit to those experiencing dementia with services being more linked up/streamlined. It was commented that to aid early prevention having individuals attend short memory tests when they reach a certain age could be beneficial to early diagnosis.

*Reduce waiting times and making individuals aware that there is a time limit on NHS support*

*Do not have telephone appointments with the dementia sufferer trying to gauge whether or not they have dementia when they can't even see the person.*

*The time between referral from GP and visit to the consultant could be shorter*

*Have a specialist who can offer a range of support with e.g info, Benefit entitlement, progression of the condition, support to Carers.*

*Diagnosis is a post code lottery and unfortunately it starts at GP level. A better understanding and awareness of dementia is required in all GP surgeries which will then hopefully encourage people to come forward at an early stage*

*Took a long time for diagnosis, feel this could be streamlined*

*The quality of the diagnosis and consultant, advice on what to do next, what's the point of a diagnosis if we're just left hanging? The diagnosis is focused only on the medication not the support side which should be linked immediately*



*GP don't have good testing system to diagnose dementia and can often be misdiagnosed, a dementia specialist would be more beneficial as their testing system is better*

*Make sure doctors are aware of early onset (pre 65) and listen to their patients*

*By inviting patients in for short memory tests at their GP or hospital setting when they have reached an age that the risk of them having dementia is increased significantly. My dad had symptoms for a few years, but we struggled to get him in to discuss with GP due to his fear of mental illness and Data Protection legislation.*

## 2.4 Immediate/Initial Post Diagnostic Support

Total number of responses to this section: **52**

In this section respondents were asked about their views of their experience of **immediate support** that they may have received following the initial diagnosis of dementia. Data from responses has been analysed below.

Using a scale of 1 to 5 with 1 being poor and 5 being excellent respondents were asked to rate their experience of the **support** they have received following diagnosis. The average score was **2.77**.

When asked what aspects of **post diagnostic support worked well**, **46** responses were received. It was highlighted that having a dementia specialist was an excellent support mechanism for those who were/are in receipt of this type of support. Respondents also commented that having a GP/practice nurse showing understanding and making appropriate referrals had a positive impact on post diagnostic support. It was commented by many respondents that post diagnostic support should be continuous rather than limited to the benefit of the individual living with dementia as well as to family/unpaid carers.

*The PDS worker attended within a few weeks of diagnosis and worked through some basic planning processes and made some referrals which my father found reassuring and helpful*

*The Practice Nurse that initially referred my dad to memory clinic has been very good at helping with my dad's medication whenever we call, so we don't have to keep repeating his history to a new clinician each time*



*Fantastic help/knowledge of dementia support worker but too limited in frequency and stopped too soon*

*Having access to a dementia specialist for advice and information about the condition*

*As mentioned previously young onset dementia in Fife have a specialist nurse who gets to know you through the diagnostic process and then remains with till end of life. She provides support not just for me but also for my family with regards to health and well-being. This service is excellent and should be maintained indefinitely.*

*Referring to other agencies*

### What aspects did not work well

It was also noted by some respondents in this section that the **post diagnostic support did not work well** for them with the statements below being recorded:

*We have no support*

*No follow up support as yet*

When asked how **post diagnostic support could be improved**, 45 responses were received. Respondents who received support for the first year regarded it as a positive support mechanism but after diagnosis identified that continuing support was required as one year was not enough. An increase in support organisations was identified as an improvement along with clear sign posting to services and support. Again, the theme of involving family members more was highlighted in this section.

*Once the year is over, you are left in limbo as who do people turn to when there is deterioration in dementia. You have to go back to the doctor who then refers back to consultant. Going in circles. Improve the after care.*

*My dad still had capacity post diagnosis and was able to complete ADL himself, we needed help further down the line and we're informed contact your Dr. I can't remember the last time Dad had a dementia specific check up with a specialist*



*More support organisations will be more handy to have as soon as a diagnosis has been*

*The dementia support worker was excellent and knowledgeable but the support was too infrequent and stopped not long after diagnosis. It's very short sighted as dementia sufferers need more support as disease progresses - not less.*

*Availability and provisions should be clearly sign posted to all*

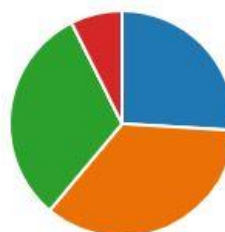
*Direct contact with family*

Respondents were asked how easy is it to access the post diagnostic support available about dementia to meet your needs? **54** responses were received:

16. How easy is it to access the **post diagnostic support** available about dementia to meet your needs?

[More Details](#)

● Not at all easy	14
● Not very easy	19
● Fairly easy	17
● Very easy	4



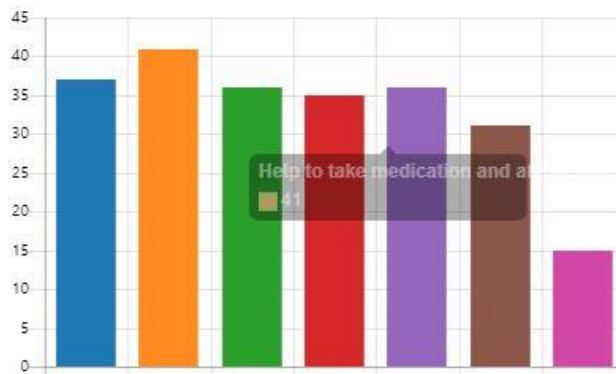
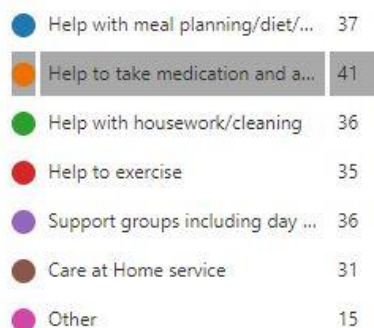
## 2.5 Living Well and Independently Long-Term with Dementia After Diagnosis

Respondents were asked what support they needed after diagnosis to live as normal a life as possible with the condition – 7 examples were given along with the option to state “other” to allow for respondents to state anything that was not covered in the examples. Multiple answers could be given. Results were as follows:



18. Once diagnosed what support do you need to live as normal a life as possible with the condition? Examples might include:

[More Details](#)



The top answer was “Help to take medication and attend doctor/nurse appointments.

Second was “Help with meal planning/diet/cooking”

There was a joint score for third/fourth place “Help with housework cleaning” and “Support Groups including day care settings”.

Respondents were asked what **support they needed from the local community** to live well with a diagnosis. This section generated a large number of comments and suggestions from **44 respondents**. A large portion of respondents highlighted the need for reducing social isolation by having more varied local activity groups, volunteers and befrienders including respite/support for unpaid carers; educating the community to dementia; increasing dementia friendly outlets and having access to transport. One respondent commented that having dementia type villages/gated communities where individuals with dementia could go about their daily lives in a safe environment. Below is a selection of comments that reflect the main suggestions from respondents:

*....I would like to see my Mum be supported to socialise... most things are online this does not work for my Mum. I would love to have a trusted person pick my Mum up and deliver her to a social event ( dementia focused) to build her confidence and being out meeting people and being able to talk to someone other than only me. ....i would love to see more Dementia friendly communities especially gated self-contained communities where people can be safe to go about their daily lives. Even just to have someone visit her for a chat once a week would be good.*

*Prevent social isolation. Folks with dementia end up being isolated from friends.*

*More volunteers to befriend, provide companionship, provide transport to take me out and about or to appointments.*

*More varied 'day' centres provisions to enrich life e.g., music groups, activity groups - perhaps 2 hour sessions to help stimulate those with dementia. A lunch club.*



*Exercise has never been mentioned. Even support to go out for a walk in the fresh air would help. As before it would be useful to have one person as a facilitator*

*Various dementia friendly outlets/activities to be available*

*A dementia cafe Like Mood cafe would be a good thing to have as we can share information, experience and help each other with advice and understanding*

*Better transport links*

*More activity for carers to get some respite which would mean someone having to look after the individual with diagnosis.*

*Educate the community on dementia and the issues people experience who suffer from the illness.*

One respondent in this section highlighted support from social work as being a very positive experience:

*My mother receives excellent support from the Kirkcaldy SW Team. I am extremely grateful for the support my mother receives and for the ongoing support I receive. I honestly can't thank them enough; they have been amazing.*

Using an open text box question, respondents were asked to tell us in a few words about their **experience of hospital or health care support after being diagnosed** to which **45** people responded. The majority of respondents reported that support was lacking, difficult to obtain with some reporting they have received no support/care at all. However, those who did receive support or health care commented that they found it very helpful with positive comments regarding support from Alzheimers Scotland and Fife Carers. One respondent fed back that the information they received too much information, commenting that condensed information may be more suitable.

*Had to do a lot ourselves to get social work involvement*

*The overall experience from health was good. I was disappointed with the GP as I felt I was actively discouraged from seeking a diagnosis for my mother. I feel that we should be actively working in partnership to diagnose Dementia at the earliest stage possible, in order to provide the supports required.*



*Little or no contact with patient since being diagnosed left for family to provide support. Dementia sufferer lost ability to cook and prepare meals in Sept this year. Cannot get any help with this at all now mid-November, relying on one family member to help 7 days per week. Told this is not classed as personal care which I know it is. Level of support is non existent*

*It's challenging when being passed between services. My sister and I want to care for our parents at home. The health and social care process does not support this.*

*Consultants and nurses alike do need more dementia awareness training. Recent experiences in hospital have lead me to be ignored by consultants who would only speak to my wife and nurses who have questioned my diagnosis of dementia because of my age.*

*I'm not aware of any follow up health care support following diagnosis.*

*Appalling - nothing available - had to set up our own support. unless you have carers and service, that actually covers all areas (we are always being told... 'oh well, of course, you fall in between things in your postcode!!!' fife is not a huge area so services are clearly prioritised for areas with more population.*

*Post diagnostic care support team and fife Carers have been very helpful*

*I felt that we received lots of information - at times too much. We understand that support is needed but a condensed version may be easier to use.*

*Assistance from Alzheimer's and Fife carers was vey good. Trying to access social care was a nightmare, long waits, reluctant managers, high thresholds at every level meant constant battles with officials when trying to access services Shortages of paid carers, respite, and care homes places were just a few of the problems. NHS capacity in accessing mental health services was problematic whether getting access to consultants or residential care etc.*





## 2.6 Future and Emergency Planning and End of Life Planning

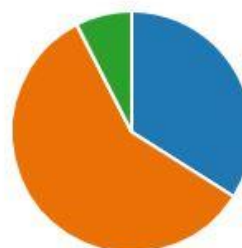
In this section respondents were asked about their plans and preparations for living well with dementia. There were 5 set questions which respondents were asked to select from YES/NO/Don't Know answers. The questions and results are recorded below:

**Q. Do you have a plan in place which notes your personal wishes for the care and support you wish to receive as your dementia condition progresses?** (to which 53 responses were received)

[More Details](#)

[Insights](#)

Yes	18
No	31
Do not know	4

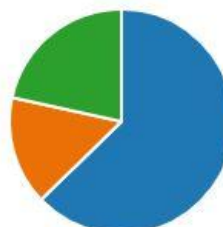


**Q. Do you think you would benefit personally from having support to make future plans and/or emergency plan or to review an existing plan?** (to which 51 responses were received)

[More Details](#)

[Insights](#)

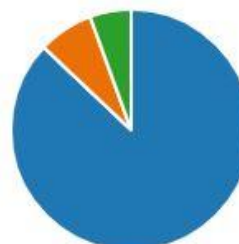
Yes	32
No	8
Don't know	11



**Q. Do you have a Power of Attorney in place so that those who care for you are able to act on your wishes in the future?** (to which 54 responses were received)

[More Details](#)

Yes	47
No	4
Don't know	3

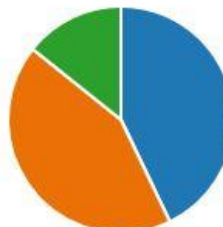




**Q. If you do not have a Power of Attorney in place, do you think you would benefit from having support to arrange one so that those who support you can make decisions in your best interest, on your behalf?** (to which there were 7 responses)

[More Details](#)

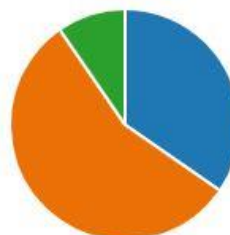
● Yes	3
● No	3
● Don't know	1



**Q. Have you considered or put in place arrangements for your end-of-life care such as finding out about a care home or sharing your wishes with someone?** (to which there were 52 responses)

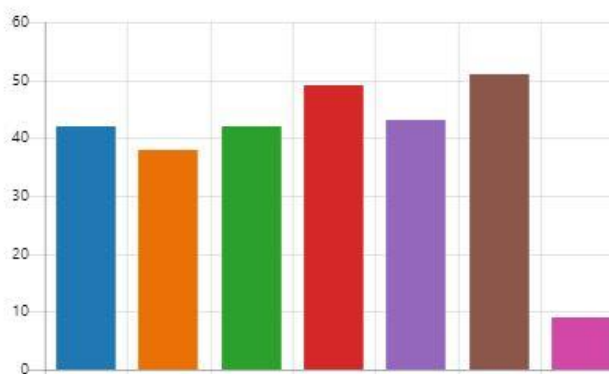
[More Details](#)

● Yes	18
● No	29
● Don't know	5



Respondents were asked what support or information they thought should be available to help those living with dementia to plan for their future. There were 6 examples given for which respondents were asked to tick all that applied with the option to state “other” to allow respondents to state anything thing that was not covered in the examples. Results were as follows:

● Information and templates to ...	42
● Information about Power of A...	38
● Information about courses of ...	42
● Information about what supp...	49
● Information about support gr...	43
● Information about the suppor...	51
● Other	9



**The top answer was “Information about the support available for your family or carers”**

Second answer was “Information about what support may be available”.

Third being “Information about support groups for people living with dementia”.



## 2.7 Improvement Priorities for Fife’s New Dementia Strategy

In this section respondents were asked to what extent they agreed or disagreed to 7 provided statements about the priorities for Fife’s dementia strategy.

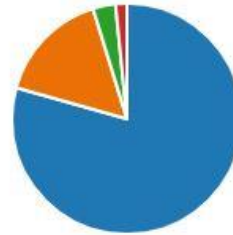
### Statement 1

“Fife should do more to improve diagnosis rates and ensure a timely diagnosis of people with dementia”

[More Details](#)

[Insights](#)

● Strongly agree	50
● Tend to agree somewhat	10
● Tend to disagree somewhat	2
● Disagree	1



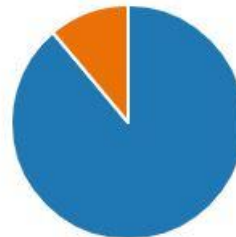
### Statement 2

“Fife should ensure high quality more targeted or specific information about dementia, local services and support is available to all those with a dementia diagnosis and their carers”

[More Details](#)

[Insights](#)

● Strongly agree	56
● Tend to agree somewhat	7
● Tend to disagree somewhat	0
● Disagree	0



### Statement 3

“Fife should develop care and support services to meet the needs of people living with dementia and their carers, to maintain independent living and avoid crisis”

[More Details](#)

● Strongly agree	59
● Tend to agree somewhat	2
● Tend to disagree somewhat	2
● Disagree	0





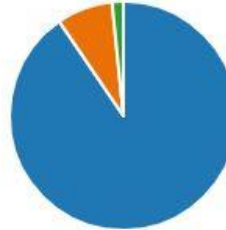
**Statement 4**

“Fife should provide more support for people living with dementia who can no longer live at home without support”

[More Details](#)

[Insights](#)

Strongly Agree	57
Tend to agree somewhat	5
Tend to disagree somewhat	1
Disagree	0



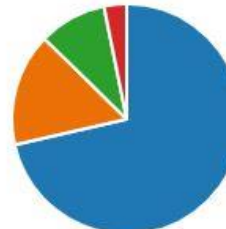
**Statement 5**

“Fife should provide high quality hospital care for people living with dementia”

[More Details](#)

[Insights](#)

Strongly agree	45
Tend to agree somewhat	10
Tend to disagree somewhat	6
Disagree	2



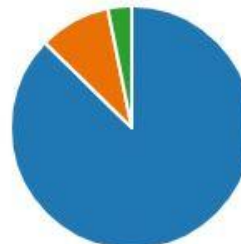
**Statement 6**

“Fife should provide high quality alternatives to hospital care for people living with dementia”

[More Details](#)

[Insights](#)

Strongly agree	55
Tend to agree somewhat	6
Tend to disagree somewhat	2
Disagree	0



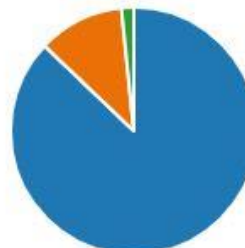
**Statement 7**

“Fife should support to plan for high quality end of life care”

[More Details](#)

[Insights](#)

Strongly agree	54
Tend to agree somewhat	7
Tend to disagree somewhat	1
Disagree	0





## 2.8 Your Priorities for Improvement

In this section respondents were asked list their top 3 priorities to improve their experience of living well with dementia. **50** responses were received.

### Analyse quotes on spreadsheet

Respondents were asked to rank the top 5 most important priorities for them for support and information under 3 different sections. Each section listed suggested priorities for respondents to rank with 1 being the most important.

#### Diagnosis and Awareness

\*\*\*Scott to insert graph from STATS given by Ann

Social and Health Support \*\* paper copies were different from on-line

\*\*\*Scott to insert graph from STATS given by Ann

Practical Support – Day to Day Living \*\* paper copies were different from on-line

\*\*\*Scott to insert graph from STATS given by Ann

## 3. Conclusion

In conclusion of analysing the results of this report highlighted that improving information is a high priority for the majority of respondents. Accessibility of information, conciseness, and consistency with the benefit of being directed to this information at the right time were highlighted. The diagnosis process could be improved from the initial stages with an emphasis being placed on the importance of GP's awareness of dementia and taking time to listen to family members/nonpaid carers. It was commented that good communication not only between services but also with family members/nonpaid carers and the person living with dementia was key to making the process a more positive experience. The results of this report identified that a timely diagnosis was placed as the highest priority by many respondents with post diagnostic being the second highest priority. Responses stated that continual specialist support from the point of diagnosis throughout the journey of on individual living with dementia would be hugely beneficial both to the individual and family members/nonpaid carer.

Social isolation was identified as a key issue for those living with dementia, with many placing "Staying Connected with Family Friends" as a high priority when considering social and health support. Living independently at home with appropriate levels of support was also identified as a main priority by most respondents. Both social and peer support and staying active and well were identified as important and valuable.



It is recommended that consideration along with findings from the participation and engagement workshops (Appendix 1) be given to the priorities identified by respondents in this consultation for inclusion and contribution to Fife's Dementia Strategy Review.



Appendix 1



## **Fife Dementia Strategy Review**

### **Workshop Feedback**

[Ann Reynolds]  
[24 November 2021]

## **Contents**



## 1. Introduction and Methodology

Fife Health and Social Care Partnership have completed the collection of feedback through engagement activities with those who live with dementia, those who support someone living with dementia including paid and unpaid carers.

Fife Health and Social Care Partnership launched the consultation on 20 September 2021.

The Public Engagement Team have facilitated 12 face to face workshops throughout Fife as well as hosting 2 on-line workshops with various stakeholders seeking their views and opinions to provide a fair representation of Fife's dementia needs. The face-to-face sessions followed the structure of participation via conversation and interactive worksheets directed by 5 'themes' that would encapsulate the individuals' dementia journey from pre diagnosis to the now:

- What I enjoy in my life right now
- What has gone well
- What is important to me
- What could be improved
- What is missing

Participants were encouraged to write down their thoughts/views/opinions on the interactive worksheets. One participant requested that information sent via email to the Public Engagement Team be recorded as feedback as part of the engagement and participation process. These points were duly recorded as requested. The feedback was then recorded and grouped into the following categories that emerged through discussion:





- Community Groups
- Information
- Benefits
- Transport
- Diagnosis
- Family
- Wellbeing
- Care and Support
- Housing/Other

The online sessions followed the same structure as the face-to-face workshops. Participants engaged in open discussion, had use of the chat box function on Teams and notes were taken by the Public Engagement Team to record opinions and views for feedback to be included in the response.

Feedback within this report has been collected via each of the methods described above. Participants were also informed of the on-line consultation/survey that was being launched on 09 November 2021.

As public reference group the existing group STAND (Striving Towards A New Day) which is a peer support group for those with early onset dementia was used. This group tested our approach for suitability and sense test purposes. Representatives from this group were also present at various sessions to support facilitation and to “oversee” the workshops were run accordingly and fairly representing the citizens of Fife. Funding for this purpose was donated by Innovations in Dementia.

In total 16 workshops were planned throughout Fife (Appendix 1) 4 were cancelled due to no participant registrations and 3 on-line workshops were planned with 1 being cancelled due to no participant registrations.

## 2. Workshop Feedback



The findings recorded below are from the face-to-face interactive workshops and are based on direct feedback from participants who attended the sessions and are categorised for analysis purposes using the five main themes as set out above. The groups comprised of the following: - members from STAND; those who live with early onset dementia; those who live with dementia; unpaid carers and paid carers/support workers as well as one individual who has a personal interest in community research on the subject of dementia.

## 2A: Theme - What I Enjoy in My Life Right Now

Participants were asked to discuss what they enjoy in their lives right now. Responses created topics through conversation with most of the feedback on this theme promoting the value of community groups where individuals felt involved and had a sense of purpose. Participants across most groups conveyed the importance of community groups as a great community asset where support, friendship and advice could be sought.

### Community Groups

Participants discussed in-depth with enthusiasm the value of community groups.

*"Self-confidence has returned. Proud to provide help and support to others".*

*"Doing activities that I am good at" (skilled joiner)*

*"Using previous skills to research dementia which has helped me - talking to other people helps me cope - gives me a constructive use of time - without it I would sink".*

*"Dementia Friendly Community"*

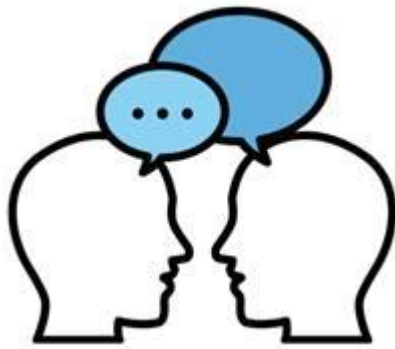
*"I love dropping my dad off at Later Life Choices - when I pick him up I know he had a great time"*

*"Great friendship through peer support group (STAND)"*

*"I love this group - the bus comes to get me - without it I would be lost"*

### Family and Friends

Participants discussed the importance of family and friends recognising the value they bring to each other's lives.



*"The company of daughters to talk to - they always include their dad"*

*"Being with friends is important to me"*

*"Time spent with my husband"*

### Health and Well-being

Participants highlighted during discussion activities that promoted their health and well-being.

*"Socialising and have a cup and a biscuit"*

*"Healthy walks outside/arm chair exercises"*

*"Staying active for mental well-being"*

*"Meeting every week to help me understand new way of living" (at community group)*

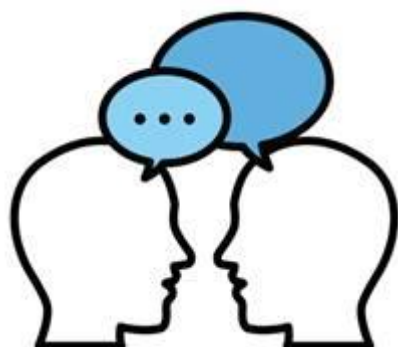
*"My garden and being outside"*

*"Doing physical activities while I am still able"*

### Care and Support



Participants during conversation on what they enjoyed in their lives highlighted how support whether it be receiving support or giving support had a positive impact on their lives.



*“My befriender and the time I spend with him”*

### *“Being a support mechanism”*

The general feeling when considering what participants enjoyed in their lives was that without community groups many would be at a loss. Those living with dementia highlighted the importance of creating friendships, having the opportunity to partake in activities that were of interest to them, having a sense of being valued and understood were vital elements of enjoying life – all of which were found within a community group setting. Participants also discussed the importance of family support and friendships out with community group settings as key factors in living an enjoyable life.

It is also worth noting that both those living with dementia and those who supported someone living with dementia gained enjoyment from being a support mechanism to their loved ones and others. The value of having a befriender was also discussed as a key component to enjoying life.

## **2B: Theme - What Has Gone Well**

Participants were asked to consider what has gone well in their lives from the point of diagnosis until now. This theme generated a more varied response with participants sharing their views and experiences over a wider range of topics. The main topics in theme focussed on community groups and support with some discussion around family, information, and diagnosis.

### **Community Groups**

As with the previous topic, community groups stood out as something that had gone well in the lives of participants – again the general feeling across the groups was of community groups being invaluable particularly with regards to learning from others experience and gaining support.



*"STAND's progress is key because its welcome extends to people before and after diagnosis. This is crucial given the adverse impact of Fife's assessment backlog on people, communities and the economy" (unpaid community researcher)*

*"Knowledge of dementia was increased - speaking to others/sharing tips"*

*"Volunteer organisations are good to help you to find out about other places"*

*"Community Groups - couldn't cope without it - talking to people that understand"*

*"As a carer it was speaking to people that helped me - you get to listen to people with experience"*

*"Social Groups in the community - Later Life Choices is Fantastic"*

*"Fife Council resilience and community groups have been fantastic throughout COVID - please continue with these invaluable services!"*

***"Conversations with others helped us make sense of mum's condition - in a state of mourning for loss of something/someone that is still there - her own hopes and dreams"***

### **Family and Friends**

Participants through discussion revealed that in many cases relationships with family members became closer. The importance of family and support workers creating positive relationships was also highlighted as key in supporting someone with dementia.

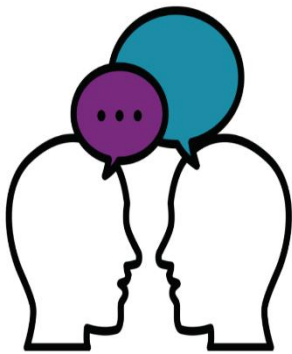


*"good family support - we took turns" (unpaid carer)*

*"closer relationships with family/friends that support/care for me"*

*"great relationship with the family helped me support the person" (paid support worker)*

*"Those that had family/carers at home - helped them (those with dementia) get on-line"*



***"People seem to listen more from friends and family rather than from professionals – we need more peer groups for this"***

### **Care and Support**

Participants during conversation highlighted that support from family, friends, paid/unpaid carers along with legal support had a positive impact on how their lives living. Conversation generated around this topic gave a diverse range of views and experience offering insight into the positive impact of paid support services (both private and public funded) within the community.



*"We had private help who popped in at night and 4 mornings per week - my dad paid for this"*

*"At the early signs we went to a solicitor to get power of attorney - what a difference that made"*

*"Insulin given by nurses every morning - helpful to myself and husband just seeing someone else"*

*"Viewforth Day Services at Queen Margaret was brilliant" (stopped because of COVID)*

*"Care staff who showed terrific compassion" (towards father in residential care)*

*"By the carer being there - just that hour gives the husband a break" (paid support worker)*

*"The 45 min service I get at home for my husband is really good"*

*"Good support from occupational therapy team"*

*"When people do come through the door they are getting really good services and activities - cognitive stimulation " (paid day service staff)*

*"Our outreach support service - we provide person centred 1 to 1 support - they really benefit from that" (paid day service staff)*

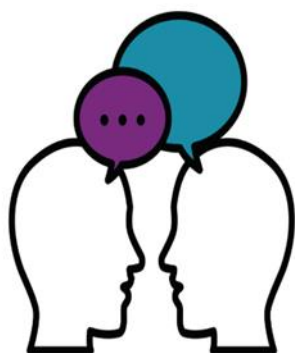
*"I get carers to help me shower/take meds - I over dozed myself a long time ago (by accident) ...I couldn't do without my carers they keep me safe"*

*"Encouraging more people to use on-line services and new technology - especially during the pandemic"*

***"We learned more about service users when we did 1 to 1 home visits when restrictions eased - in a group environment you don't get that - the one silver lining" - day services staff***

## **Information**

Participants discussed what went well when considering information on dementia and support.



*“A lot of good support/help/advice comes from word of mouth”*

*“Fife Carer’s were good – they helped me find out about benefits”*

*“Technology can be helpful – it’s about finding out what works for you”*

## Diagnosis

Participants during conversation were asked to think about what went well with the diagnosis process at the start of their dementia journey. The feedback evidenced that those living with early onset dementia had an overall positive experience during the diagnostic stage. Interestingly participants who were diagnosed later in years reported that their experience was less positive, and this is evidenced under the theme “what could be improved”.

*“I saw specialists from the start, so my medical experience has been good with my body and mind but as a human socially I didn't exist”*

*“Post diagnostic support”*

*“Pre Diagnosis and Post Diagnosis Support” (younger onset)*

## 2C: Theme - What is Important to Me

Participants were encouraged to discuss what is important to them. This theme produced a great deal of discussion highlighting inclusion and general wellbeing. Care and support were discussed with emphasis on person centred consistent support being crucial to those living





with dementia. Community groups again were recognised as being an invaluable community asset.

### Community Groups

Community groups were highlighted by many participants as an important part of their lives particularly with regards to socialising and having informal support networks.

"Being allowed to grow - others still trusting me with topics/projects of value"

"Having other people to talk to - the groups are a life-line"

"Socialising is so important"

"Social groups and speaking to people going through a similiar journey as a carer"

"local group and contacts"

"We need groups that ask people what they are interested in - not everyone likes dominoes - support needs to be bespoke"

***"STAND's progress is key, because its welcome extends to people, before and after diagnosis. This is crucial given the adverse impact of Fife's assessment backlog on people, communities and the economy".*** (individual with personal interest in community research)

### Wellbeing

Discussion around this topic was very much focused on individuals being treated as individuals with their own needs, feelings and thoughts, with conversation bringing to the fore that being an unpaid carer can affect relationships as family "roles" have changed.



*"Being treated as me, and not someone with dementia"*

*"Keeping their interests alive..." (unpaid carer)*

*"It's important to know the person when providing care"*

*"Recognising that people with dementia have their own and feelings - getting family and friends to recognise this"*

*"Treating them with dementia not as having learning difficulties" (unpaid carer)*

*"Cognitive stimulation is important"*

*"Being treated as normal as possible and not being discriminated"*

***"I want to be a son to my dad.... not his carer who is the bad guy and have to do his private care. I need some help, so me and my dad spend time together as father and son"***

### **Care and Support**

Care and support were recognised as being important by participants with an emphasis placed on consistency of carers and having a knowledge of the person who is receiving support. It was evident that both those providing informal care and support were keen to continue with this role and to support their loved one at home - consistency and carer support are required to enable this to continue. Recognition was given to the importance of the dementia nurse/specialist team in supporting individuals and their



families.

*"Consistency in staff"*

*"It's important to know the person when providing care"*

*"Family and friends as support"*

*"It never occurred to me that I wouldn't be able to do this - I can't do it all myself, I thought I could" (unpaid carer)*

*"Being able to stay in my own home with my wife and family"*

*"Having the same carer or perhaps 2 carers - people with dementia need routine and familiarities "*

*"Social care and assistance for carer respite"*

*"Care is not person-centred - it should be"*

*"Keeping people out of the "system" for as long as possible - ensuring their carers have the information and support they need"*

***"I strongly encourage Fife to ensure that there is always someone in the Dementia Nurse post. This is key in taking people from diagnosis to bereavement, and in providing essential help-line and other support"*** – individual with personal interest in community research

## 2D – Theme: What Could be Improved

Participants in this theme generated detailed discussion looking at various elements of care and support. A vast range of feedback was collected taking opinions and views from the start of individuals' dementia journey through to where people are at now. Discussion was also lively when considering the diagnosis experience. Participants also highlighted that information and access to benefits needs to be improved. Transport was also discussed



during this theme and although public transport is available it is considered high risk to those with dementia travelling alone.

## Care and Support

The general feeling across the participant groups was that care and support packages are too difficult to access; there is a need to involve family members more; day care services appear to be reducing; consistency in care and support is required along with an increased awareness of dementia; respite and flexible support for unpaid carers needs to be improved and post diagnostic support could be improved for those living with dementia.

*"We heard a few months later (after diagnosis) from Whytemans Brae - twice we had visits then this stopped - no input for 2.5 years - 1 visit from the post diagnosis dementia team - then COVID came - we were then taken off the books"*

*"Family need to be involved not kept out of the loop - they need to know the family"*

*"You need a social work assessment to access respite - if I don't get this I will be dead! I would pay but don't know where to go - I'm not confident to choose"*

*"There is a lack of awareness on how to support someone with dementia - capacity is compromised - 'the right to choose' sometimes has been overlooked"*

*"Communication between services - seems to be a lack of attention to detail when delivering the working package"*

*"End of life care"*

*"Staff knew he had dementia but didn't know the implications of it - he had ran out of milk - she said "I told him that he needed milk yesterday"*

*"Medical teams in general wards need to have awareness of dementia and how to deal with it"*

*"Accessibility of services (for unpaid carers) - flexibility outwith working hours"*

*"Specialist dementia day care seems to have taken a step back ...transport has been cut, personal care has been cut, numbers services are able to support is now minimal"*

*"There seems to be a lack of services in rural areas - not the whole of Fife is covered"*

*"Social work involvement wasn't great - it was like a tick box exercise"*



***“Care at Home is a big issue - there are lots of people waiting - for those that are getting it they are getting it later, so they are missing out on our service - and that its crazy - it seems to be disjointed”*** – day service staff member

## **Diagnosis**

Participants were encouraged to share their views and experience of the diagnosis process on their dementia journey. A common theme within this topic was that of older persons being diagnosed with dementia felt that that diagnosis process needs to be improved to enable access to medication and support. It was conveyed that some participants found doctors/psychiatrists were hesitant to diagnose dementia which in turn held up accessing appropriate care and support which had a detrimental effect on their overall well-being. It was felt across all groups that doctors and other professionals should listen to the family/carers more as it is them who notice the difference/decline in the individual the most. However, it must be noted that those who live with early onset dementia found the diagnosis process and post support to be a more positive experience but, in some cases, they too experienced hesitation from the medical field in making an actual diagnosis.



*"Doctors need to listen more to the individual i.e. more knowledge of people living with younger onset of dementia"*

*"Psychiatrist was hesitant in diagnosing - it was my wife who saw the signs herself in her 40s - it was in her 60s until she was diagnosed"*

*"Most professionals don't recognise it as a disease"*

*"GPs must listen to carers/family members - as they are the ones who see the change"*

*"I am angry about everything - it took 3 years to get diagnosis - that's 3 years of missed medication"*

*"Early diagnosis - there was a lack of support for men of a working age (possibly women too)"*

*"GPs could be more responsive from early stages"*

*"People with Deaf(ness) are often misdiagnosed as often it is put down to hearing issues not dementia"*

*"When diagnosed it's great you get the meds but it's the wait for diagnosis"*

***"Post diagnostic teams are short staffed and can't get around everyone - it's not a lack of will/want they are just so short staffed - it's an amazing template that isn't working as they are short staffed"*** – day service staff

### **Information**

A common theme throughout the various workshops was that of information. Participants fed back a variety of experience and views on this matter. Some reported that information was patchy; not consistent; difficult to find with some participants noting that more information should be available either at point of diagnosis or soon after.



*"Whoever diagnoses dementia should say "here this is how you apply for/entitled to claim/information on what benefits are available"*

*"A buddy service would be good - better than the GP giving you a list of websites"*

*"Information about groups/support/advice needs to be repeated regularly not just mentioned at diagnosis or the occasional doctors appointment"*

*"Information about the use of technology to help with dementia and be more independent"*

*"Information has to be standardised across the country"*

*"Information about Power of Attorney in the early stages"*

*"Information coming from social workers was minimal"*

**“At one point when you got a diagnosis you were referred to post diagnostic team - supposed to give out info - that support was for 1 year - if delay in diagnosis where else do you get that info?”** – day services staff

## Benefits

During the workshops access to and information about benefits was an area that was felt by all that could be improved. Participants fed back that applying for and being assessed for self-directed support was a complicated process. There was a strong feeling that being able to have access to self-directed support would enable a greater level of independence and could prevent crisis situations. Some participants noted that they did not know what benefits they may be entitled to claim.



*"No-one told me I could have applied for carers allowance"*

*"Housing, benefits info "*

*"The key is SDS so they can "buy" what service they want"*

*"SDS criteria is set at critical and it's a complex process"*

*"We need SDS before it becomes a crisis situation"*

*"SDS is the way forward but getting it is difficult - only allocated when critical"*

*"SDS would enable so much more independence"*

***"A lot of people still don't know they can access certain benefits - there are so many things people still don't know they are entitled to" – day service staff***

## **Transport**

Participants recognise that transport is a key component to supporting them to live an independent life, access services and support. The general feeling was that in rural areas participants had to travel to get support. Day services staff fed back that due to social distancing measures they were restricted as to how many service users could access their transport to attend the group setting. Participants also expressed that if they were able to access transport to go to an activity their unpaid carer could have a break.





*"Support to do things - either transport or a support worker so I can go to golf/pool - give my wife a break"*

*"We live in the outskirts and have to travel to get support"*

*"We should not have to rely on volunteers to drive - us it should be statutory"*

*"Due to lockdown cannot get transport to go to church"*

*"Fife buses are great but my wife struggles to lift my wheelchair on the bus and because of COVID she's had to do it on her own"*

*"Because of social distancing we can only have a maximum of 8 in transport" (day services)*

*"If the bus driver shouted "next stop is....." that would make a huge difference"*

*"To go on his own to activities without me would be great"*

***"Transport is there but it's high risk for people with dementia on their own"***

FHSCP Dementia Project Manager

## 2E: Theme – What is Missing

Participants during the workshops were asked what was missing from their point of view to help them with their lives on their dementia journey. When considering this theme participants fed back in detail about Care and Support Services and Information as being areas where there were important elements missing that would have a positive impact on living with dementia/supporting someone living with dementia. Comments were also noted regarding the diagnosis process, benefits and housing.

### Care and Support

When considering what was missing with care and support a large amount of conversation was generated. Participants identified that day services appeared to be reducing due to



restriction with numbers of people that could be supported were limited. It was also identified that day care services were not suitable for all and that other support should be available. Access to a specialist/nurse team was also thought to be missing for those over 65. Unpaid carers identified that they would benefit from training and where required support overnight - both of which would enable the individual with dementia to remain at home longer. Participants also felt that they would benefit from having a “caseworker” who would support them throughout their time living with and supporting someone with dementia – someone to guide them to information and services. One participant also raised the relevant point of language (BSL) being supported when someone was moved into a care home.

*"Day services for those that cannot do their own personal care (we are not funded for that)*

*"Day care isn't for everyone there has to be alternative support available to people"*

*"We've taken a step back..we are not providing transport, we are not providing personal care and the numbers we can support is minimal - it's a big issue" (day services staff)*

*"Moving and handling training for unpaid carers" (unpaid carer)*

*"Lack of continuity in care"*

*"We need 24 hour care at home"*

*"Home support prior to moving into care (lack of)"*

*"We need access to a specialist nurse/service - those under 65 get this -but those over 65 are age-discriminated"*

*"A case worker - connection with services"*

*"There should be dementia training in every GP practice - from receptionists to GPs"*

*"It's important that if a Deaf person is moved into a care home that supporting their language is crucial "*

***"24 hour care at home is needed - it's getting up through the night - if someone is double incontinent this is how they end up in a care home" – unpaid carer***

## **Diagnosis**



Participants when considering what was missing from the diagnosis process commented that dementia should be acknowledged as a long-term terminal illness, commenting that it was felt more investigation was required at the start of the diagnosis process. A main point that has been commented previously was that of the point of earlier assessment for diagnosing dementia.



*“Dementia should be acknowledged as a long-term terminal illness”*

*“There is a lack of investigation at the start of diagnosis”*

*“Why are we not assessed earlier?”*



## Information

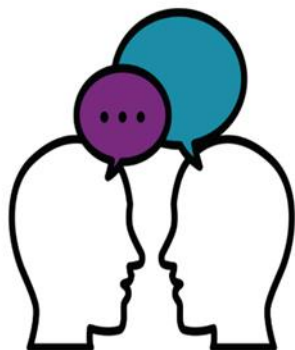
The main feeling around information from participants was that of information should be easier to access and ideally there should be one place to go for information that will help support and guide people to what support, service and benefits are available to them. Participants also noted that information regarding power of attorney requires specialist advice. One participant also mentioned that there was a lack of information in BSL regarding dementia and services and support that are available.



**“Should be one port of call where you get all the information - or given a number to say ‘we are here to help you’”** – day service staff

## Benefits

Participants felt that access self-directed support payments were missing and that by having this independence could be improved.



**“Everyone getting SDS now - would make such a huge difference rather than waiting to be assessed as critical”**

**“Awareness of self-directed support”**

**“SDS would enable so much more independence”**

## Housing

During the workshops only a few participants raised the topic of housing. However, there were a couple of statements from participants that are worth noting that raise the point of suitable housing and funding to adaptations.





### 3. Conclusion

To conclude the findings of this report, participants identified the importance of community groups as having a positive effect on their lives. The ability to meet with others for informal peer support was highlighted along with the opportunities to create lasting friendships and reducing social isolation. It was noted that for more people to access community groups that transport and/or a befriender/support worker would be a great benefit. Participants also acknowledged that family and friends and maintaining good relationships were vital with some reporting an increase in closeness since diagnosis.

Physical activity was noted as a key component for maintain good health and wellbeing, however without the support of others there is a risk that the individual living with dementia may not be able to attend activities to meet this need.

Participants discussed the impact of family “roles” changing since diagnosis and becoming an unpaid carer. It was identified via the sessions that the majority of unpaid carers want to offer care and support to those living with dementia but in order to be able to continue to do so support from services was required. Unpaid carers report that many of those living with dementia are awaiting a package of care with some reporting that having access to self-directed support would alleviate some of the pressures of unpaid carers. The general feeling was that access to self-directed support should be easier and should be allocated before crisis situations for early intervention and to maintain, and in some cases increase independence.

Participants fed back that day services offered valuable support for those living with dementia but due to the current pandemic services have been restricted in the numbers that can be supported. Day services were viewed by participants as a valuable community asset and individuals who wished to attend day services should be able to do so when not assessed as being critical. It was recognised that day services are not suitable for everyone and in such cases there should be suitable alternative activities/groups available. Although participants could identify positives that arose from the pandemic – it was stated that there is no alternative to face-to-face support.

Information regarding dementia and support/services available generated a lot of discussion points. Information should be consistent and standardised, easier to access and ideally there should be one point of contact for information from the point of diagnosis right through to the end of someone’s dementia journey. Participants highlighted that specialist information regarding power of attorney should be easier to access.

When considering the diagnosis process, participants stated that actual diagnosis should be quicker with some participants noting hesitation from consultants/doctors in giving a diagnosis. Feedback gathered stated that participants felt that GPs and medical practices should be better trained in dementia and dementia awareness and that family members should be more involved. Participants expressed that a delay in diagnosis meant a delay in receiving medication which is crucial for many who live with dementia.



Discussion around Care and Support generated a large amount of discussion with the main themes across participant groups stating care and support packages are too difficult to access; family members need to be involved; consistency is required along with an increased awareness of dementia by those who deliver care and support. A need for respite and flexible support for unpaid carers was identified as a required improvement. However, it must be noted that those who do receive a package were mainly positive. Participants fed back that it is important for carers to be compassionate and build good working relationships with family. It was highlighted that there is a need for 24hour care within the home setting to reduce the need for admission to care homes and to enable unpaid carers to continue to provide care and support. When considering housing and adaptations it was commented on that provision of housing nearer to community service and bus stops appears to be lacking. One participant commented that they had paid for adaptations to their home as no funding was available.

Accessibility and availability of transport was discussed amongst participants. Transport to take individuals to activities would be of great benefit to both the individual living with dementia and to their unpaid carer.

It is recommended that consideration be given to all the above points for inclusion and contribution to Fife’s Dementia Strategy Review.

## 4. Appendix 1

### Timetable of Workshops

Date	Location	No Participants	Comments
20/09/2021	Kennoway	11	STAND members
22/09/2021	Tayport	4	
23/09/2021	St Andrews	4	
27/09/2021	Anstruther	1	
05/10/2021	Kincardine	Cancelled	0 registrations
07/10/2021	Inverkeithing	Cancelled	0 registrations
08/10/2021	Kinghorn	10	
11/10/2021	Kennoway	4	
12/10/2021	Leven	Cancelled	2 reg participants cancelled
22/10/2021	Glenrothes	2	
26/10/2021	Dunfermline	2	
27/10/2021	Cowdenbeath	2	
28/10/2021	Cupar	5	
29/10/2021	Dunfermline	Cancelled	1 reg participant cancelled
02/11/2021	MS Teams	2	



03/11/2021	MS Teams	3	Day services staff
04/11/2021	MS Teams	Cancelled	0 registrations
09/11/2021	Kirkcaldy	1	Individual with personal interest in community research
15/11/2021	Glenrothes	10	Later Life Choices group
Totals		<b>61</b>	



## Appendix 2

### **Introduction**

Fife Health & Social Care Partnership (a partnership between Fife Council and NHS Fife) is seeking your views on our approach to support people living with dementia to live well for longer.

Our last strategy covered a 10 year period from 2010 to 2020. In that strategy we set out a series of realistic and achievable service improvements and developments with the aim to better meet the needs of people living with dementia and their carers.

The number of people whose life is affected by dementia has increased since our last strategy was published and is forecasts to continue to increase by a third over the next 10 years. The increase in demand for support from people living with dementia, and those unpaid carers who support them, must be balanced against the call demand on the public resources that are available.

Together we need to decide what will make the greatest different to those living with dementia. It's for this reason that we need to hear your voice as we develop our new strategy for the future.

Your responses to this questionnaire, together with the feedback from a range of other public engagement exercises, will influence the improvement and investment priorities in Fife's next dementia strategy. This is your chance to let us know what matters most to you, what will make a positive and lasting difference to your experience of living with dementia or caring for someone who does.

What is your experience of dementia and dementia support in Fife? What do you feel will be most important to you in the future? Your opinion really matters. What should Fife do to improve support for those who have direct experience of dementia?

Your response will remain confidential and will be used only for the purpose of informing the development of our Dementia





Strategy. All questions are optional and you do not have to answer questions that you feel uncomfortable with. The more responses we get the better understanding we have of your priorities.

The consultation has several parts:

1. Section 1 is where we learn a little about you.
2. Section 2 is about your experience through the pathway of the disease
3. Section 3 asks about your views of our improvement priorities for our next dementia strategy.
4. Section 4 are a set of optional questions to help us to ensure our plans are equitable and work for everyone
5. Section 5, the final section, asks for your contact details if you want us to stay in touch with you.

Thank you in advance.



## Section 1 - About you

This section will help us to understand who is completing the questionnaire. Where possible we would like to hear directly from the person living with dementia. If you are an unpaid carer, please answer the following questions in respect of the person you care for.

Are you:

- Living with dementia
- Providing unpaid care to one or more people living with dementia
- A paid professional in dementia support/services including social care support workers/personal assistant
- Volunteering to support people with dementia

At what stage of the illness would you say your dementia [or the dementia of the person you are caring for] has progressed to?

- No illness or symptoms
- Pre-diagnosis with some symptoms
- Mild illness
- Moderate illness
- Severe illness
- Advanced or End stage illness

If you are living with dementia or caring for someone with dementia, how long ago did you receive your diagnosis?

- In the last year
- 2 – 4 years
- 5 – 7 years
- 8 - 10 years
- More than 10 years
- Uncertain/not sure



Do you [or person living with dementia you are caring for] also live with another life limiting or chronic illness?

- Yes
- No / Nothing diagnosed

If you answered yes to the question above, please specify what the life limiting or chronic illness is?

- hypertension (high blood pressure)
- depression
- coronary heart disease (CHD)
- stroke or transient ischaemic attack (stroke or TIA)
- diabetes
- Parkinsonism
- Epilepsy
- Cancer
- Weight loss or eating disorder
- Incontinence
- Chronic obstructive pulmonary disease (COPD)
- Asthma
- physical disability
- sensory loss
- Other

Fife Health & Social Care Partnership already has a dementia strategy. Please rate your awareness of it.

- Don't know anything about it.
- I am aware there is a strategy but do not know what it says
- I am aware of the details in the strategy



## **Section 2 - Your experience of dementia services and support**

### General Information and Awareness of Dementia

In this section we would like your views of the **general information and awareness of dementia**. If you are an unpaid carer, please answer the following questions in respect of the person you care for.

On a scale of 1 to 5 with 1 being poor and 5 being excellent, how would you rate your experience of the **general information and awareness** you have received about dementia?

(Poor) 1            2            3            4            5 (Excellent)

Tell us what aspects of **general information and awareness** work well for you?

How could we improve the **general information and awareness** about dementia to meet your needs?



## Diagnosing Dementia

In this section we would like your views of your experience of **diagnosing dementia**. If you are an unpaid carer, please answer the following questions in respect of the person you care for.

On a scale of 1 to 5 with 1 being poor and 5 being excellent, how would you rate your experience of the **diagnosis of dementia** you received

(Poor) 1          2          3          4          5 (Excellent)

Tell us what aspects of the **diagnosis process** work well for you?

How could we improve the **diagnosis process** for dementia?

## Immediate/Initial post diagnostic support

This set of questions asks about your experience of the immediate support you may have received following the initial diagnosis of dementia. Examples of this may include support



groups, cafes, care home settings, day care settings etc. If you are an unpaid carer, please answer the following questions in respect of the person you care for.

On a scale of 1 to 5 with 1 being poor and 5 being excellent, how would you rate your experience of the **support** you have received following your diagnosis of dementia

1                      2                      3                      4                      5

What aspects of **post diagnostic support** work well for you?

How could we improve the **post diagnostic support** available about dementia to meet your needs?

How easy is it to access the **post diagnostic support** available about dementia to meet your needs?

- Not at all easy
- Not very easy
- Fairly easy
- Very easy



Living well and independently long-term with dementia after diagnosis.

Once diagnosed what support do you need to live as normal a life as possible with the condition? Examples might include:

- Help with meal planning/diet/cooking
- Help to take medication and attend doctor/nurse appointments
- Help with housework/cleaning
- Help to exercise
- Support groups including day care settings
- Care at Home service
- Other: \_\_\_\_\_  
\_\_\_\_\_

What support do you need from the local community to support you to live well with a diagnosis?

In a few words please tell us about your experience of hospital or health care support after being diagnosed with dementia? What are the things that you have found helpful, and what are some of the things that were not very helpful?

### **Future and emergency planning and end of life planning**

In this section we ask a few questions about your plans and preparation for living well with dementia. If you are an unpaid



carer, please answer the following questions in respect of the person you care for.

	Yes	No	Don't know
Do you have a plan in place which notes your personal wishes for the care and support you wish to receive as your dementia condition progresses?			
Do you think you would benefit from having support to make future plans and/or an emergency plan, or to review an existing plan?			
Do you have a Power of Attorney in place so that those who care for you are able to act on your wishes in the future?			
If you do not have a Power of Attorney, do you think you would benefit from having support to arrange one so that those who support you can make decisions in your best interest, on your behalf?			
Have you considered or put in place arrangements for your end-of-life care such as finding out about a care home or sharing your wishes with someone?			

What support or information do you think should be available to help those living with dementia to plan for their future? For example:

- information and templates to plan for the future
- information about Power of Attorney
- information about courses of treatment





- information about what support may be available
- information about support groups for people living with dementia
- information about the support available for your family or carers
- Other: \_\_\_\_\_  
\_\_\_\_\_



### Section 3 - Improvement priorities for Fife's new dementia strategy

This section will help us to develop practical improvements to ensure those people affected by dementia, both those living with the disease and those who care for them, are well supported in the future. If you are an unpaid carer, please answer the following questions in respect of the person you care for.

Do you agree or disagree that the following statements about the priorities for Fife's Dementia Strategy?

Fife should...	Strongly Agree	Tend to agree somewhat	Tend to disagree somewhat	Disagree
Do more to improve diagnosis rates and ensure a timely diagnosis of people with dementia.				
Ensure high quality more targeted or specific information about dementia, local services and support is available to all those with a dementia diagnosis and their carers.				
Develop care and support services to meet the needs of people living with dementia and their carers, to maintain independent living and avoid crisis.				



Provide more support for people living with dementia who can no longer live at home without support.				
Fife should...	Strongly Agree	Tend to agree somewhat	Tend to disagree somewhat	Disagree
Provide high quality hospital care for people living with dementia.				
Provide high quality alternatives to hospital care for people living with dementia.				
Support to plan for and access high quality end of life care.				

### Your priorities for improvement

In just a few words, what would be your top **three** priorities to improve your experience of living well with dementia? You can include things not mentioned above if these are more important to you.



1 -
2 -
3 -

In the following question we are trying to assess what information and support is most important to you. We can use this information to prioritise the types of support that are most valuable to you.

Please rank the **top five most important priorities** for you, with 1 being most important.

### Diagnosis and awareness

	Rank of importance
General information about dementia	
Raising awareness of dementia in my community	
Receiving a timely diagnosis	
Post diagnostic support for first year	
Help and support to be involved in planning services for the future	
More work and emphasis to ensure Fife is 'Dementia Friendly'	
Staff knowledge, skills and understanding	



## Social and Health Support

	Rank of importance
Social and peer support	
Staying active and well	
Help with activities and day services for people living with dementia	
Support to maintain good physical fitness	
Help to access digital services and support	
Social prescriptions should be part of everyday support planning	
Accessing health care/hospital appointments	



## Practical Support – Day-to-day Living

	Rank of importance
Support to develop a pathway of care that meets my personal needs	
Information and access to practical support that may be available to me locally	
Living independently at home	
Help with daily living and personal care	
Staying connected to family and friends	
Planning my discharge from hospital	
Help for the person who carers for me	
Information about financial support that may be available	
Support with future planning such as, where I live, who I live with, care settings, and making decisions about my future.	
Help to prepare my personal emergency plan	
Help with palliative care and end of life planning	

***Thank you for taking the time to be part of this consultation***



## **Section 4 - Equalities, diversity & inclusion questions**

We use the information in this section to understand who is responding to our consultation and engagement exercises. By completing this it will help us to ensure we have representation from the broadest set of people as possible. This helps to ensure our services and communications reach every part of the community.

The information provide here will be separated from your main consultation response and will be held only for monitoring purposes relating specifically to this consultation and for no other reason. The information will remain confidential although each question also offers you the chance to decline to answer.

If you are an unpaid carer, please answer the following questions in respect of the person you care for.

**What is your age?** *Please tick **one** box only below.*

- 54 or younger
- 55 – 59
- 60 - 64
- 65 – 69
- 70 - 74
- 75 – 80
- 81 or older
- Prefer not to say

**Are you?** *Please tick **one** box only below.*

- Male
- Female
- Prefer to self-describe
- Prefer not to say

**What is your sexual orientation?** *Please tick **one** box only below.*

- Bisexual
- Gay man
- Gay woman/lesbian



- Heterosexual/straight
- Other
- Prefer not to say

**What is your ethnic group?**

- White
- Mixed or multiple ethnic group
- Asian
- Black
- Other ethnic group
- Prefer not to say

**Section 5 – staying in touch after the consultation**

One of our priorities is to keep in touch and continually involve local people to ensure what we offer remains relevant. In order to do this we need want to keep the channels of communication open.

*Are you interested in giving your views at a later stage, including responding to questionnaires or attending various meetings to talk about living with dementia or on relevant topics?*

- Yes, please add me to your engagement list
- No, please do not contact me again about consultations

Would you like to be added to our mailing list to receive information from time to time? *Please tick one box only below.*

- Yes, please add me to your mailing list.
- No, please do not add me to your mailing list.

If you ticked 'Yes' to either of the last two questions, please provide us with your name or e-mail address, or if you prefer, your postal address.





Name: \_\_\_\_\_ E-mail: \_\_\_\_\_@

Postal Address: \_\_\_\_\_

***Thank you for taking the time to be part of this  
consultation.***