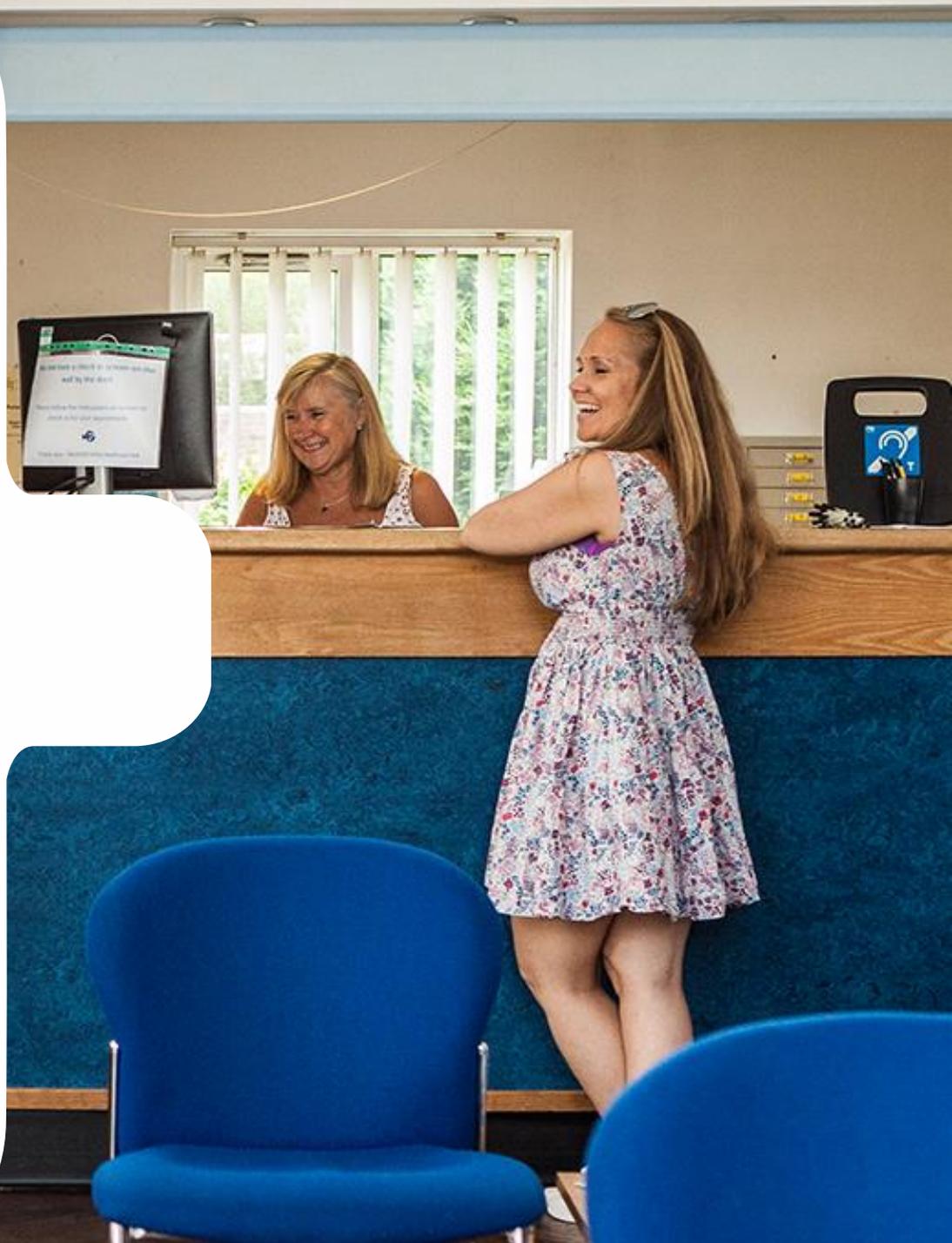


Here

Brighton and Hove Memory Assessment Service Benefits of enhanced support service

Case studies of patients who have received enhanced support from Memory Support Workers

Memory Assessment Service & Alzheimer's Society
Lesley Reeves, Louisa Marchant & Tiffeny James



Introduction

In 2016 we redesigned the Memory Assessment Service following feedback from people using the service that for most – 70% - diagnosis was not as important as support.

We are now at a place where we can start to understand the impact that the changes in our service have had on the experiences of people using the services. These stories are real – though the names aren't. We are excited about what we're learning. You can find out more about our work on our website.

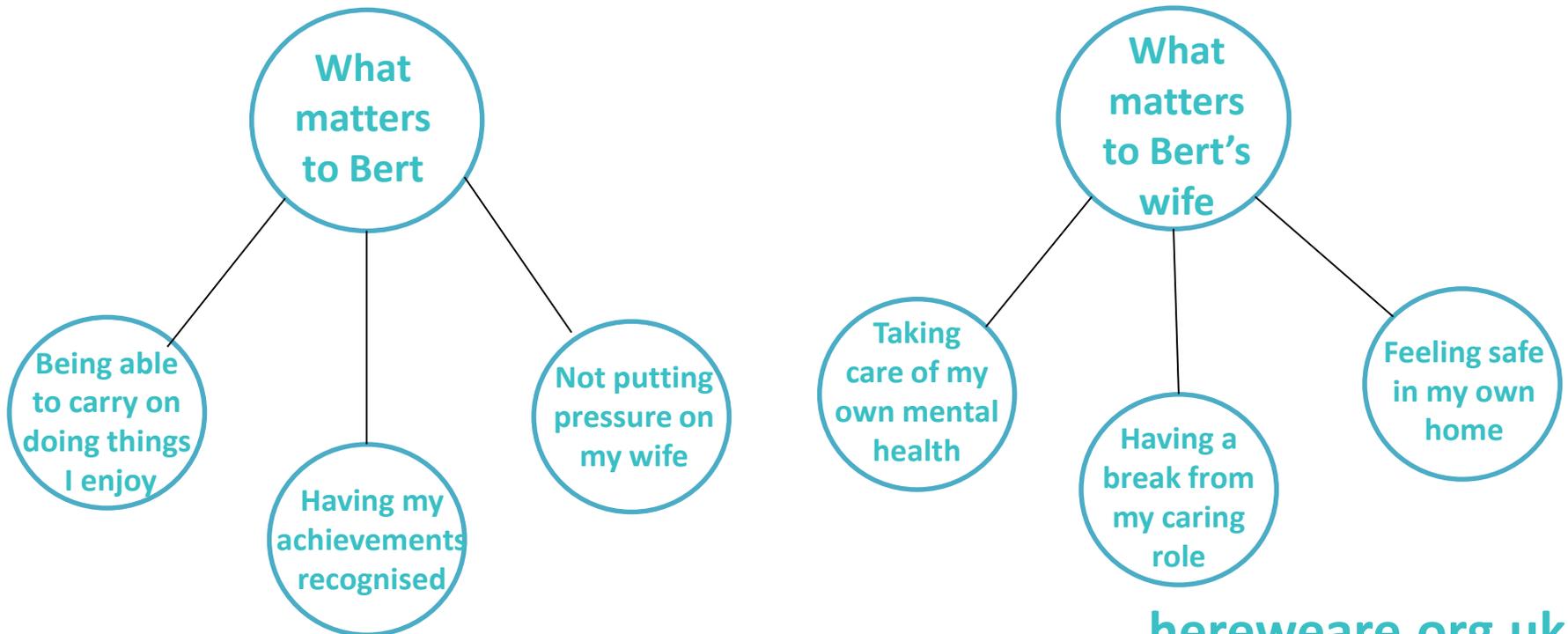
Patient stories

hereweare.org.uk

Bert

Bert is an 86 year old man who started showing aggressive and unusual behaviour, as reported by his wife who is his carer. Bert has a history of alcohol abuse and continues to drink 10 units of alcohol daily. Bert was a pilot and is very proud of this. He has now lost most of his sight which is something that upsets him greatly.

Bert was diagnosed with MCI in April 2016 and had a reassessment in December 2016 where the nurse noted Bert's behaviour changes and the stress this was causing his wife. Bert's wife is starting to neglect her own mental and physical health.



What we did

Home visit

2 MSWs responded quickly to concerns and offered a home visit before Bert's diagnosis to offer support to him and his wife

MSWs spoke separately with Bert and his wife so they could speak freely about their home situation

Bert and his wife both felt that the aggressive behaviour was an isolated incident due to a chest infection and were no longer worried

Bert's wife was encouraged to engage with the carers centre but she did not feel that this was necessary as she felt Bert's behaviour had returned to normal

Bert was encouraged to engage with Wellbeing services but did not want to do this

Bert and his wife were given contact details for a number of local support services as well as for their MSWs

Phone call from Bert's wife

Bert's wife called MAS a few weeks later saying she was overwhelmed and unwell herself. She explained that Bert had deteriorated and she needed support and was *"unsure of who else to contact"*

MSWs raised a safeguarding alert and made an urgent referral to Access Point to arrange respite for Bert

Bert's diagnosis appointment was bought forward and MSW arranged to be present for it

After investigation, Access point referred onto Specialist mental health, enhanced duty team (EnDu) due to the complexity of Bert's case

MSWs listened to Bert and his wife who told us they felt overwhelmed with the number of professionals involved and so took a step back

EnDu have taken the lead and are offering support for Bert and his wife

Bert

Without enhanced service

- Bert and his wife would have only received support following a positive diagnosis of dementia. They would not have received any support in the time between his reassessment and diagnosis.
- During the two months between assessment and diagnosis, without input Bert's rapid deterioration would have likely ended in crisis due to a break down in the relationship between Bert and his wife, and a deterioration of their physical and mental health.
- If MSWs were not able to visit Bert and his wife before his diagnosis, they may not have felt able to call MAS during their time of need.
- If Bert had received another diagnosis of MCI he would have been put back on MAS waiting list for reassessment and he and his wife would not have been able to access any support from MAS.

Principles met

- You have the right to have help as you enter the service. We will help those who love/care for you to support you.
- We will use the assessments and views of other professionals to help you.
- We pay attention to your emotional and psychological needs
- We will hold you until we have found or helped you to find solutions to what matters to you

Outcomes

- The enhanced duty team arranged temporary respite for Bert at a local care home meaning he is safe and being well looked after
- Bert's wife now reports being able to fall into a deep sleep, and sleep through the night and says she will focus on her own well-being. She is now in touch with the carers centre.
- Bert's wife visits him every day and takes him to the pub which is something they have always enjoyed doing
- The enhanced team plan to arrange a package of care to enable Bert to return home when he and his wife feel it is the right time.



“

The MSW has given me the most support out of anyone.

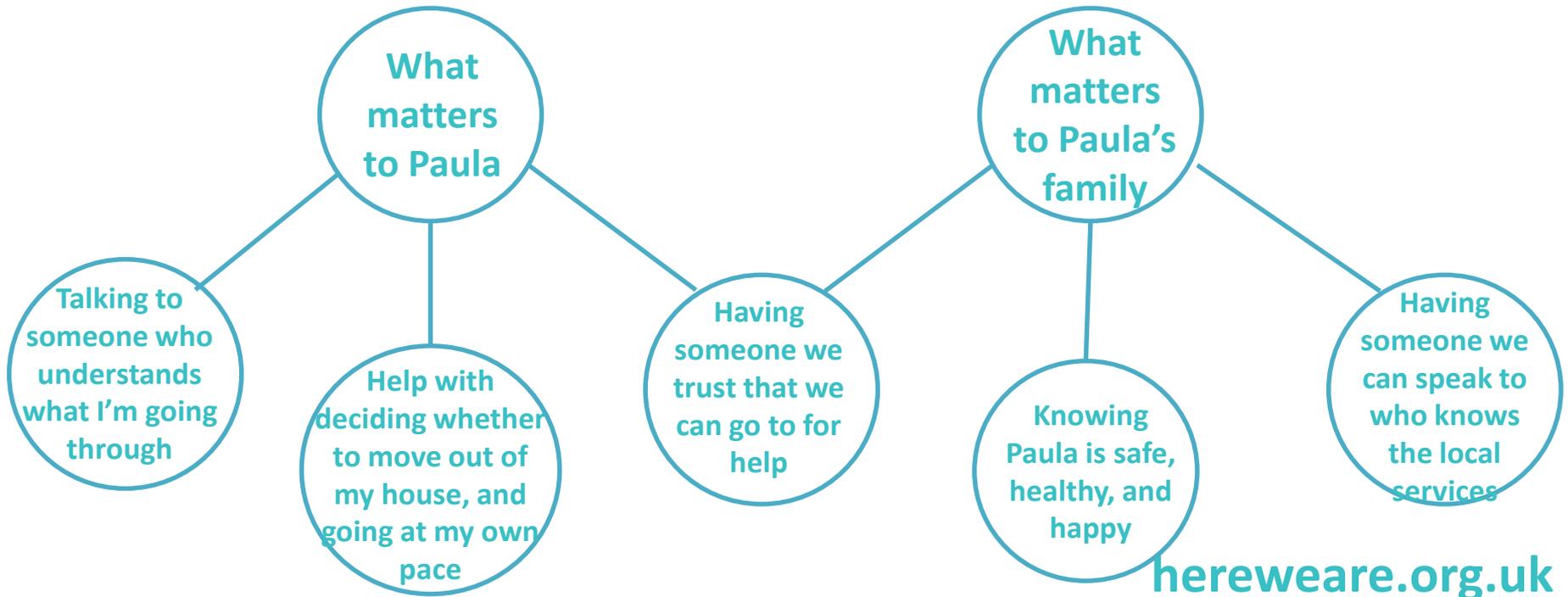
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Paula

Paula is 75 and lives alone. She has always been proudly independent having been a working, single parent. Paula has a close relationship with her daughter who lives abroad, and does not have any local family that she is close with.

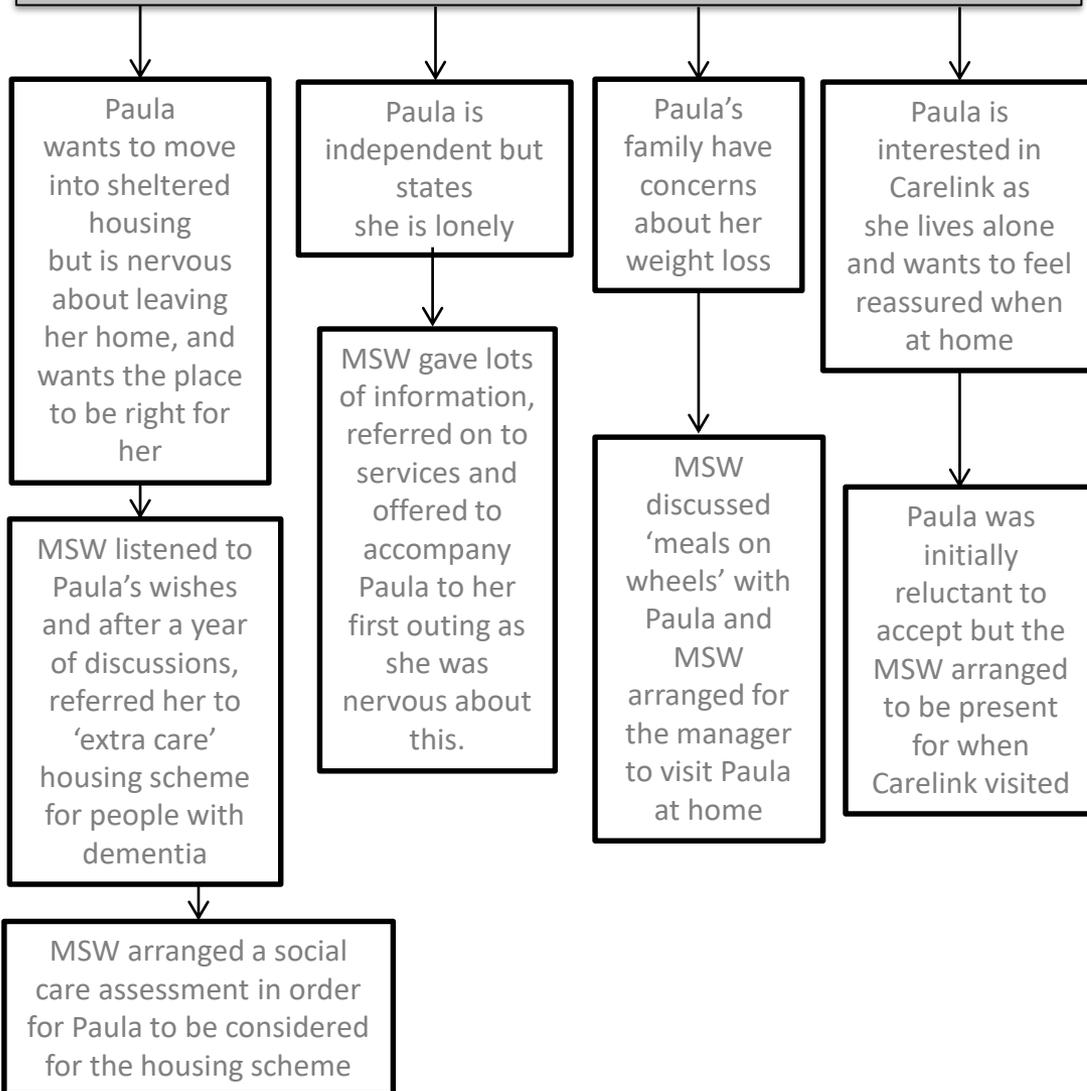
Paula has recently been diagnosed with vascular dementia and is struggling to come to terms with this. She has expressed some suicidal thoughts.

Paula is particular about her support, her home, and the people she mixes with. For this reason it has been difficult to introduce support like befriending services or lunch clubs. Paula has a great sense of fun and has an adventurous streak.

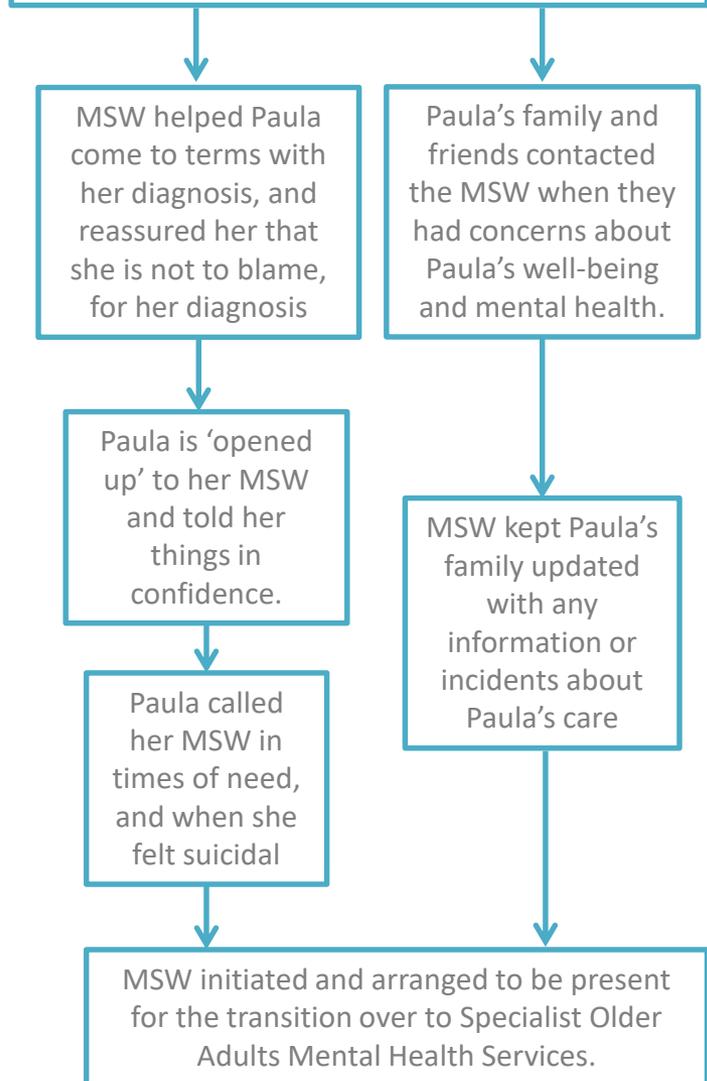


What we did for Paula

Practical support



Emotional support



Paula

Without enhanced service

- Paula would have only received one initial visit, and two follow ups, and for only the 12 months following her diagnosis. After this she would have been discharged. With only this small amount of input it is unlikely that she would have built a trusting relationship with her MSW.
- Paula would have been discharged 12 months after her diagnosis meaning the MSW would not have been able to be involved in the transition to the specialist team
- Without this relationship, Paula may not have known who to contact in times where she felt suicidal. This could have led to a crisis situation and potentially harm or death.
- Paula was very resistive to any outside support e.g. befrienders, Carelink and meals on wheels. Without the support of her MSW she may never have accepted these which could have led to further harm through isolation, falls with no way to get help, and a deterioration of physical health due to weight loss.
- It is likely that without the input of the MSW, Paula would have needed urgent input either through hospital admission or respite and would not have been able to make her own choice about where she would stay.

Principles met

- We pay attention to your emotional and psychological needs
- We will hold you until we have found or helped you to find solutions to what matters to you
- You will help those you love/care for to support you
- You set the pace and end point and you will always know where you are in our service

Outcomes

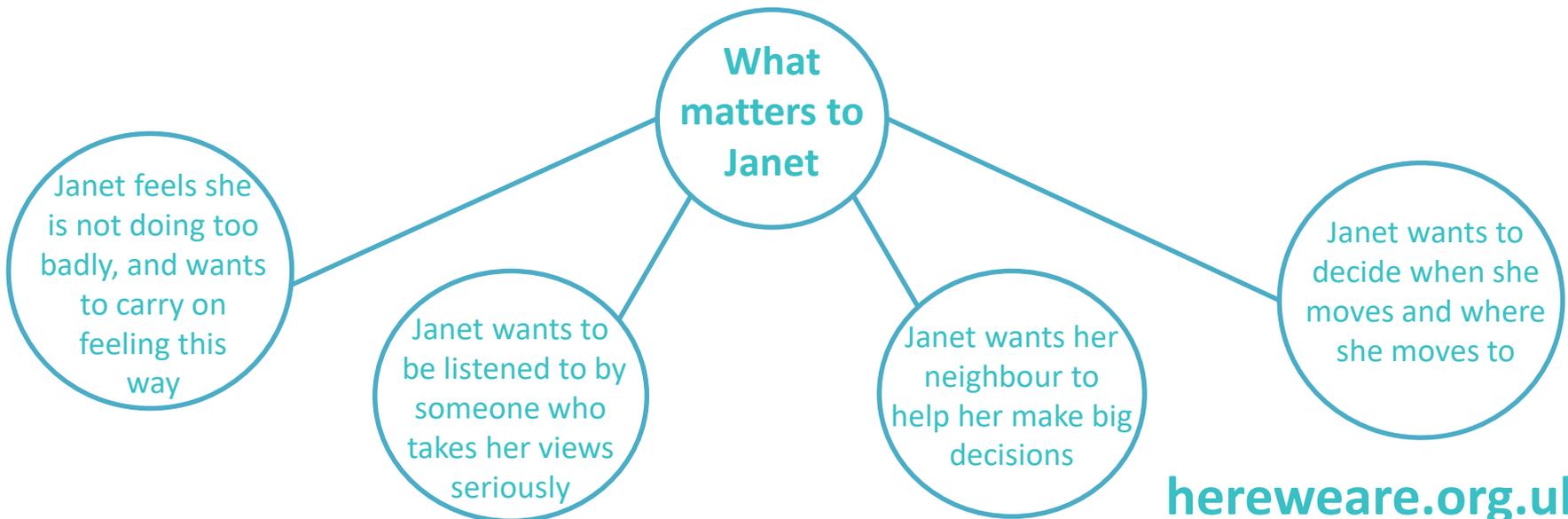
MSW visited or called Paula over 20 times during her 17 months within the service

- Paula now has Carelink at home which she feels reassured by as she can press it if she has a fall at home.
- Paula also accepted 'meals on wheels' which she says she enjoys and is helping increase her weight
- Paula has been accepted into the 'extra care' housing scheme and has been offered a flat on the top floor which she is happy about.
- Paula is still experiencing varied moods and sometimes feels as though she can't go on. She has expressed some suicidal ideation which requires more specialist input than what the MSWs can offer
- Paula contacted her MSW in these moments, and the MSW referred her onto specialist mental health team who are providing ongoing emotional and psychological support to Paula.
- It was agreed that MAS should discharge Paula and let the specialist team take the lead. MSW helped Paula with this transition and provided useful information to the service so they can support Paula in a way that suits her needs and wishes.

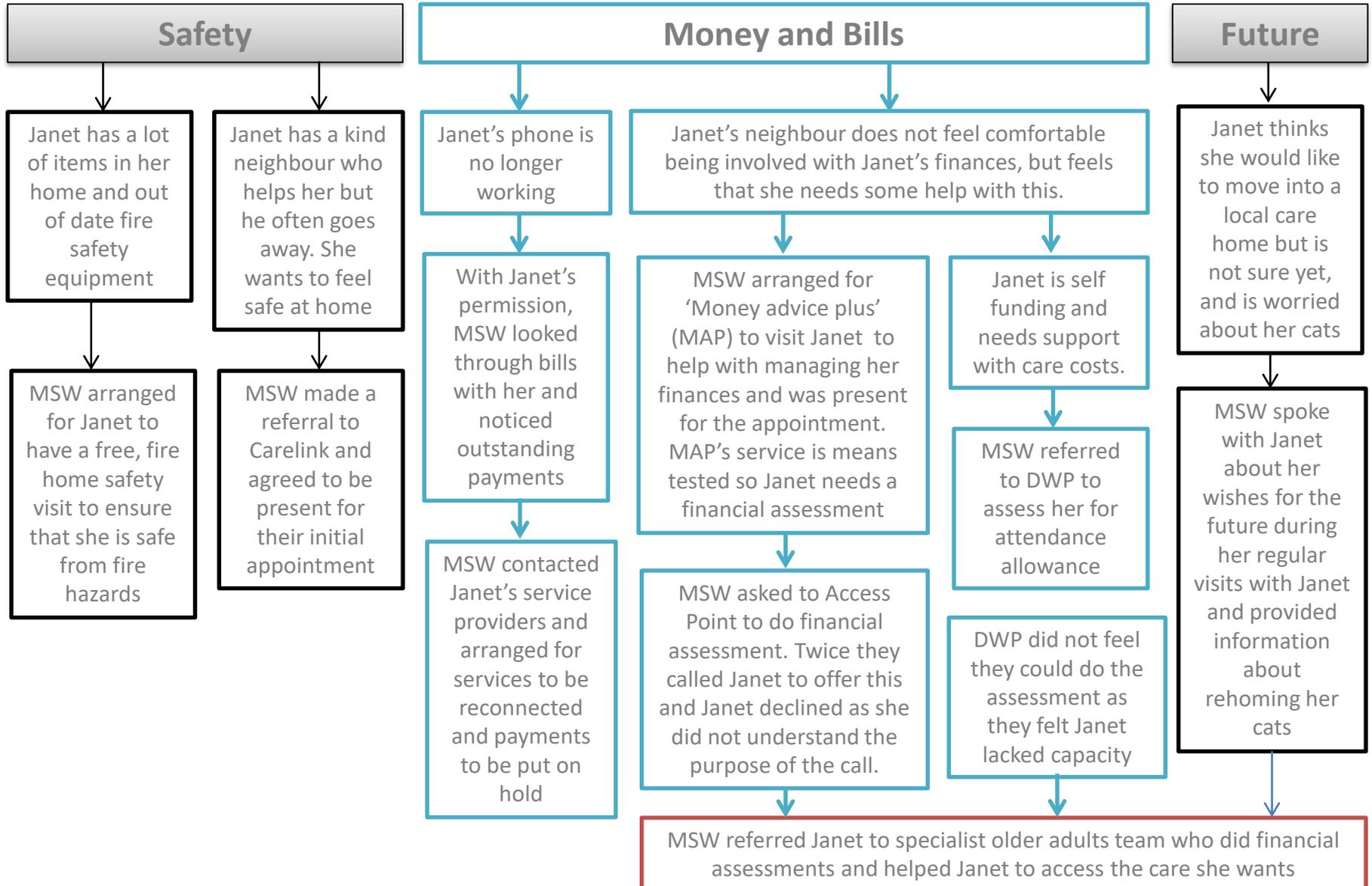
**I would really like to tell you
that I feel you really
understand perfectly the
situation and where mum is at
the moment, I couldn't
describe it better myself! You
are making such a difference,
thank you.**

Janet

Janet is 84 and since her husband died, she lives alone with no other family. Janet's husband had dementia and she cared for him. Janet has recently been diagnosed with Alzheimer's disease. Janet had been relying heavily on her friend and PoA Ann however, Ann passed away suddenly shortly after Janet received her diagnosis. Ann's daughter has now taken over PoA but Janet does not know her very well and she is not heavily involved. Without the help of Ann, Janet is struggling to pay bills, arrange appointments and manage her home. Her home and personal care has declined although Janet is not open to talking about this. Janet has a neighbour who she goes with things like letters but other than him, she does not know anyone else. Janet feels she is managing well and wants to carry on as she is however, she is at risk of self-neglect in a number of ways.



What we did for Janet



Janet

Without enhanced service

- Janet would have only received one initial visit and two follow ups from her MSW across 12 months. After 12 months, Janet would have been discharged from the service. She was not on medication and not known to any other services. Given her isolation and the risk of self-neglect and wandering, it is very likely that Janet would have reached a crisis situation and possibly come to physical harm.
- The fact that MSW could visit Janet more regularly meant they could pick up on changes in Janet's ability to manage at home and could act on problems as they arose to prevent a crisis.
- Without the MSW being involved it is likely that all of Janet's services would have been cut off. Her phone and home insurance had already been suspended and it is likely that her gas and electric would have been to meaning she would have been without warmth, light and cooking equipment.
- Janet's neighbour was happy to help her but did not want to be too involved with her finances or personal/home care. Without the regular support of the MSW he may have felt obliged to offer more care to Janet leading to carer stress and possibly even complete withdrawal of his support
- Janet declined input from Access Point as she did not understand the reason for their call. MSW was able to follow up on this with Janet, and re-refer Janet who told them a second time "I'm fine". Without MSWs input and follow up, Janet would have been left without any input. In the end MSW referred to another, more urgent service to get Janet what she needed.

Principles met

- We pay attention to your emotional and psychological needs
- We will hold you until we have found or helped you find a solution to what matters to you

Outcomes

MSW visited or called Janet over 10 times during her year in the service

- All of Janet's services were reconnected and they agreed to put payments on hold whilst MSW arranged for Janet's LPA to pay her bills.
- Janet was able to stay at home with her cats and be safe during this time, whilst she decided whether or not she wanted to move into a care home.
- Janet was able to make this decision for herself and the MSW attended a final handover to help Janet express her wishes to the specialist older adults team about where she wanted to live.
- Janet was able to maintain her friendship with her neighbour which she valued

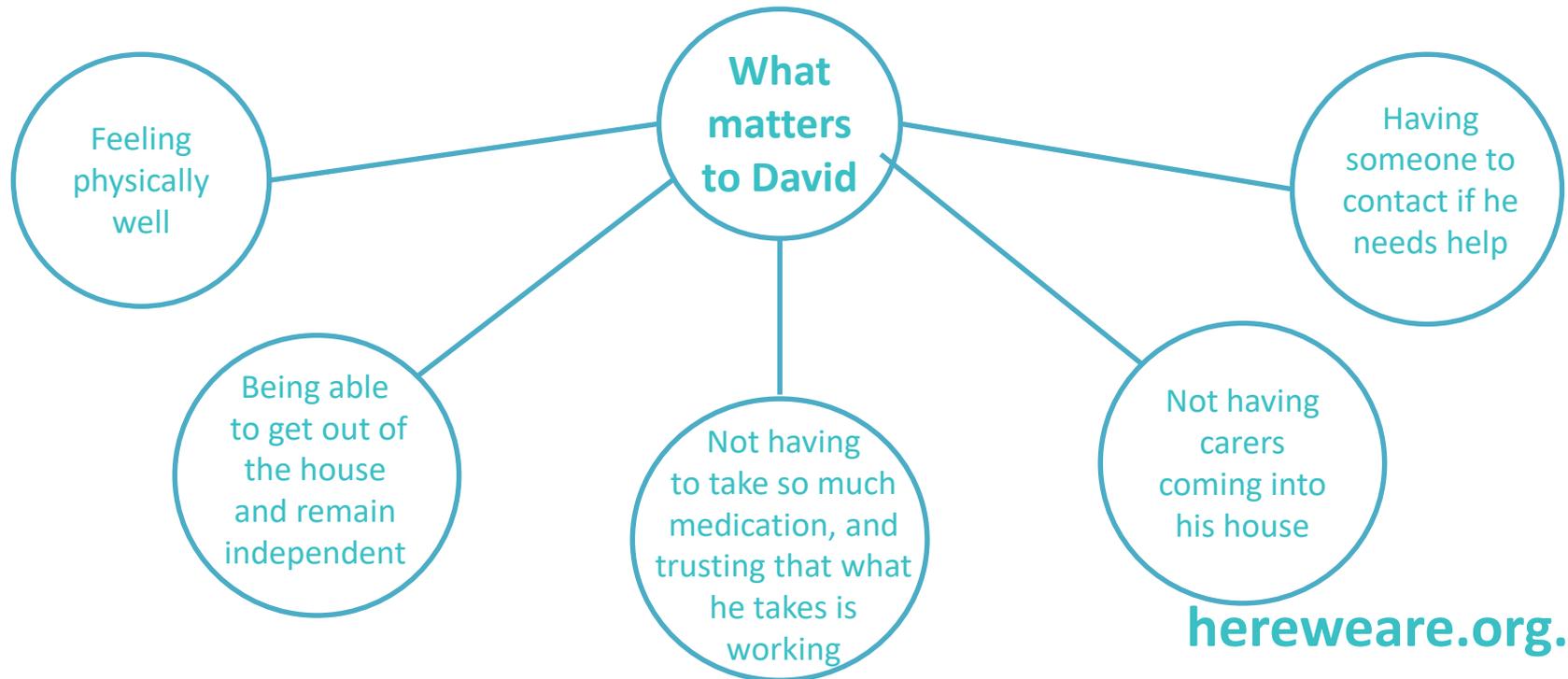
**The service we have received
(from the MSW) was excellent
– she should be commended
for the fine work she carries
out.**

David

David is a 68 year old man who lives alone, with no family and a history of alcohol abuse and homelessness. David has been diagnosed with Parkinson's dementia and has increasing care and support needs but does not want anyone coming into his home.

David feels annoyed that his "brain and body don't work" He wants to feel better but does not believe that his medication is working so quite often doesn't take it.

David wants to stay as independent as possible, and wants to be able to get out of the house. He does not have much food at home but usually goes to the pub each day for a cheap meal. If David cannot get out of the house he is a risk of self-neglect as he will not be able to eat.



What we did for David

Over the first 18 months

MSW arranged medication review for David, to reduce the number of tablets he takes and how often he has to take them

MSW visited David regularly and MAS were the only service he would engage with in terms of support

David felt able to list his MSW as a point of contact for the DWP

MSW helped David re-book missed appointments, reminded him of upcoming ones, and helped arrange transport to them

MSW set daily alarms on David's phone to remind him to take his medication

MSW discussed the benefits of accepting a care package and David gradually started to agree with this

MSW talked to DWP about David's abilities which determined what benefits he would be entitled to

MSW often took old medication away for his safety

When David was in need

David called his MSW in the Christmas period and said he was "not good". He could not explain why but his MSW knew this was unusual. MSW arrived at David's house 30 minutes after receiving his call

David had no food in the house and could not remember the last time he had eaten

David said he felt "awful" and wanted some help

David was not sure if he had taken his medication today and wanted help in taking them

MSW bought David a sandwich and chocolate bar and gave him a glass of water

MSW took away old medication and ensured that David had enough medication for the upcoming week

MSW made an urgent referral to adult social care via a safeguarding alert surrounding David's self-neglect.

David

Without enhanced service

- If David had received the basic service of one initial visit and two follow ups across one year, it is unlikely that he would have built a trusting relationship with his MSW. David was not engaged with any other services so he may not have known who else to contact in his time of need.
- David's time of need was 18 months after his diagnosis – with the basic service David would have been discharged by this time and would not have been able to contact his MSW. This could have resulted in harm if David was not able to eat
- Without the rapport between David and his MSW, it unlikely that he would have felt able to list his MSW as a point of contact for the DWP. In the past David has underreported his symptoms to DWP. David's MSW was able to advise on David's abilities so that he could access what he is entitled to.
- Without the regular contact and reminders from his MSW, it is likely that David would have continued to miss medical appointments, potentially leading to further ill health.
- it is likely that following the safeguarding alert, adult social care would have set up a care package to keep David safe and well. Initially David did not want this but through conversations with his MSW over 18 months he started to come around to the idea of carers coming in and did agree for his MSW to make a referral for him to adult social care. Without these regular conversations David may have felt that this was being forced on him, rather than it being his decision.

Principles met

- We pay attention to your emotional and psychological needs
- We will hold you until we have found or helped you to find solutions to what matters to you
- You set the pace and you will always know where you are in our service

Outcomes

MSW visited David 10 times over the 2 years that he was in the service and were able to respond quickly when he was in need

- David is now receiving a 3 x a day package of care for help with personal care, taking medication and meal preparation.
- With help in taking his Parkinson's medication, David feels more mobile and 'clear headed' meaning that he can continue to go out of the house and do things he enjoys
- David is now receiving all of the benefits that he is entitled to which can help cover his care costs
- With the package of care, someone will see David each day so he should not reach crisis point again MSWs will visit David one more time and then he will be discharged from the service.

Peer support and memory support workers

hereweare.org.uk

Peer Support Group



Background to the Group

- The group offers **peer support for people with dementia**, which makes it unique as locally there are only groups for carers
- It was set up in response to the MAS action group, and feedback given through Patient Focus Groups in 2015/6
- The group is offered as part of the Enhanced Support service by MAS, in collaboration with The 'Alzheimer's Society' and 'The Carers Centre' and is designed for people who have received a mild to moderate diagnosis of dementia through MAS
- Two separate groups run side by side on the same day, at the same time and location, meaning people with dementia and their carers can both attend
- Guest speakers from local community groups, and other partners are invited to the group eg. Hop50+, Brighton and Hove Food Partnership, Age UK

Aims of the Group

- Providing a safe, supportive space for people with a diagnosis of dementia as currently there are no other groups that offer this
- Enabling people with dementia and their carers to talk about their feelings, share experiences and swap tips
- Improving wellbeing through providing social and emotional support
- Reducing loneliness and isolation by enabling individuals to meet others and make new friends.
- Encouraging people to support each other, both inside and outside of the group
- Providing the chance to speak with people who are in a similar situation
- Supporting people to 'Live Well' with dementia and helping them to talk about what matters to them.
- Making it easier for carers to attend support groups, by providing a safe space for their loved one at the same time

Peer Support Group



Feedback about Memory Support Workers

“It’s wonderful to have this support”

(The Memory Support Worker) “showed passion and dignity towards our situation”

“We were very impressed with everything - we're very grateful, I can see there's so much support.”

The service we have received (from the MSW) was excellent – she should be commended for the fine work she carries out”

“Very kind and professional”

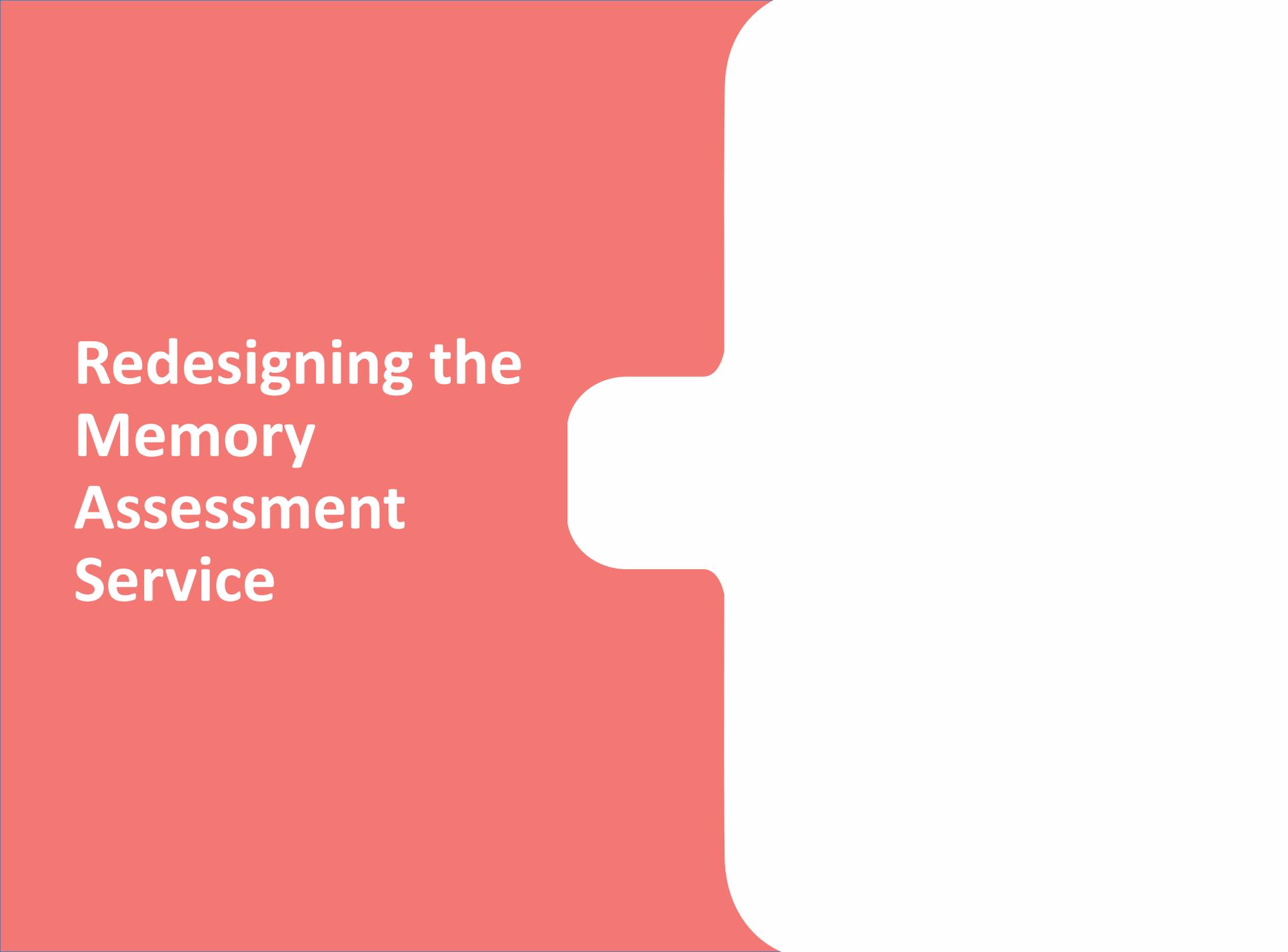
“It’s nice to know there are people out there who we can call”

“I’m very impressed with how well I’m being looked after”

The MSW has “given me the most support out of anyone”

“I’m very Impressed with how well I am being looked after”

"I would really like to tell you that I feel you really understand perfectly the situation and where mum is at the moment, I couldn't describe it better myself! You are making such a difference, thank you“



Redesigning the Memory Assessment Service

Action Group – May 2016

The action group was set up to understand

- how the current service is organised and delivered
- The impact this has on the outcomes and experience for citizens / patients and their families

We found that

- There is often a significant gap between the services we currently provide and the support people are asking for
- A focus on what matters most to people referred is needed to avoid people in the system getting lost and their needs not being recognised or responded to

Themes that emerged from action group

Assessment:

- Referrals often unclear
- Multiple, duplicated, repetitive, wasted and sometimes unnecessary
- What matters to me gets lost or not heard and we are not able to act on it
- It can be disempowering for both staff and citizens
- The focus at assessment is on achieving diagnosis and not understanding what matters
- Assessment is not always timely

How MAS have acted on this

Assessment:

- FC helps MAS to understand why the person was referred
- If a person has recently completed an assessment outside of MAS and it is suitable, we will use this rather than carrying out another assessment which can be stressful
- FC helps to identify what matters to our patients and MSWs will help patients to act on this
- MSWs can explain the benefits of assessment and diagnosis and help patients decide if they want to engage with MAS
- We understand that assessment is not a priority for everyone and will listen to what matters to help our patients access that before an assessment if appropriate
- Assessment is still not always timely, due to clinician capacity however if patients advise us that assessment is their priority then appointments can be created to accommodate the request. The clinical capacity is sourced by nurses stepping out of the MDT to deliver these assessments.

Themes that emerged from action group

Diagnosis / Treatment

- Is life changing
- There is minimal support offered to adjust

Referral / Advise

- We provide good information but no one person holds ownership of the person
- Services are not joined up and it can feel repetitive and frustrating
- The expectations of what we can offer are unclear

How MAS have acted on this

Diagnosis / Treatment:

- Is life changing. You can decide if and when you have an assessment
- You can receive support before, during and after an assessment and diagnosis

Referral / Advise

- We provide good information and will hold you until we have found or helped you to find solutions to what matters to you
- MAS have held meetings with other services that are often involved, and now work more closely together to avoid repeating work, so services are more joined up and patients do not have to repeat processes
- Patients are sent an acknowledgement letter at the point of referral with information about MAS informing patients the service they can expect and how to contact us and make complaints. In addition to this information MSWs inform patients of what they can expect from our service during the FC calls so patients and carers can make informed choices about engaging with the service.

Old System



ASSESS



DIAGNOSE/TREAT



SUPPORT/REFER/ADVISE

New System

With the new system, the patient journey can take a number of routes depending on what the patient wants and needs. Patients are held within the service until the needs are met.

First contact



Discharge

If a person decides they do not want to engage with MAS at all

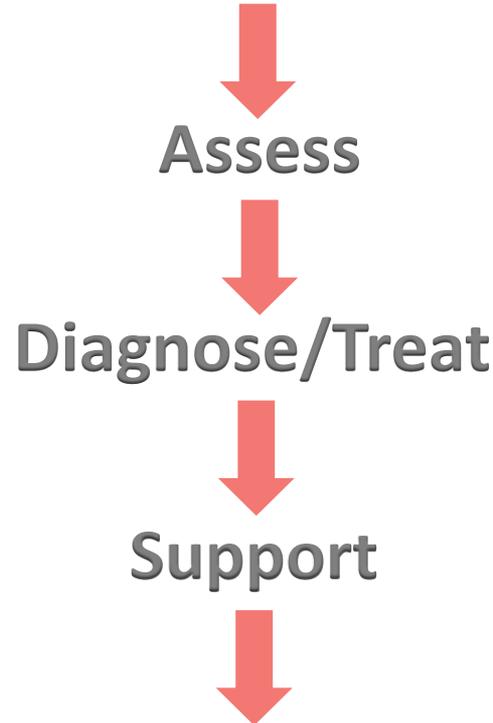
First contact



Discharge

If support needs are identified during FC and are met by onward referrals, and the person does not wish to engage with MAS or is not suitable

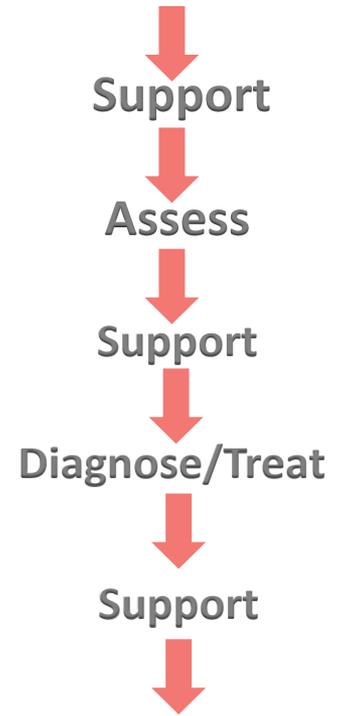
First contact



Discharge

If the person wants an assessment and diagnosis, but does not have any current support needs, they will be offered new care plan appointment after diagnosis. They will receive structure follow up appointments throughout the year

First contact



Discharge

If the person wants to engage with MAS and receive a diagnosis, but immediate support needs are identified. MSW will be involved throughout the whole MAS process until it is suitable for them to be discharged

First contact calls

Memory support workers call patients shortly after their referral is triaged, to discuss the following;

- Presenting problems and why the person thinks they were referred
- Whether or not they want to engage with the service
- Whether they are suitable for MAS – it may be during FC that the MSW identifies complex needs so refers directly onto other specialist services
- How their memory problems affect their day-to-day living
- What support they have from others
- What their current needs are e.g. support with getting out of the house or preparing meals
- What their priority is e.g.;
 - Having an assessment and receiving a diagnosis
 - Getting a package of care at home
 - Moving closer to a family member
 - Support for their carer – through referral to carers centre
 - Advice on receiving benefits
 - A befriender to help with getting out
 - Anything else that matters to the patient
- If appropriate – MSWs will book an assessment for the patient, or make a note on when they want to be contacted for an assessment.

Pre-diagnosis visits

During FCCs, MSWs sometimes identify the need for a face to face appointment with patient.

A face to face appointment may be needed if;

- It is too difficult to communicate over the phone for example due to a patient's hearing difficulties
- MSWs identify care and support needs and need more information and idea of how things are at home, in order to better understand the needs of our citizens. If referrals to other services are required these will be arranged.
- Patients want to discuss the assessment in more detail before deciding to have one – this could be because they are anxious about the assessment and the outcome, and may not be aware of the benefits of an assessment and would be reassured by a face-to-face visit

From our learning we created new service principles

Current Service principles	New Service Principles
Assessment is Harmless	We will only offer you an assessment if we or you can see a benefit. We will use the assessments and views of other professionals to help you.
Diagnosis is always useful	Diagnosis is sometimes helpful and we understand it is life changing
If you have dementia you cant access wellbeing services	We pay attention to your emotional and psychological needs.
The only help available is what we can offer you and only for 12 months	We will hold you until we have found or helped you to find solutions to what matters to you
We only offer practical support to those with dementia, and only when you have a diagnosis	You have the right to have help as you enter the service. We will help those who love/care for you to support you.
Where you live dictates what we can offer (care homes eg)	You can have the same service wherever you live (Nursing home or patients home).
We set the pace of your journey	You set the pace and the end point and you will always know where you are in our service



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Here

Sussex Partnership
NHS Foundation Trust



for brighton and hove