Information & Support Available to People Living with Dementia and their Carers After Diagnosis

Summary Report

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Healthwatch Worcestershire, Civic Centre, Queen Elizabeth Drive, Pershore, WR10 1PT
Telephone 01386 550264
info@healthwatchworcestershire.co.uk
www.healthwatchworcestershire.co.uk

SUMMARY REPORT

ABOUT HEALTHWATCH WORCESTERSHIRE

Healthwatch Worcestershire (HWW) gathers feedback about local publicly funded health and care services and makes recommendations to those who run them about how they could be improved from a patient, service user and carer perspective.

WHY THIS WORK

'My memory…. I remember the past but can't remember recent conversations …maybe I'll remember fractions of that …. I can't remember names but can remember things that have happened in the past… I'm just jogging along. I know what's coming down the line and I've just got to do my best' Person living with dementia, Interview

'Vascular dementia gives you a feeling of grief though no one has died, a feeling of having your heart ripped out every day, a feeling of, no matter how positive you try to be, something else happens' Carer, written submission

The National Institute for Clinical Excellence[1] describes dementia as:

'Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person's ability to carry out daily activities…. Dementia is a progressive condition, which means that the symptoms will gradually get worse.'

Worcestershire has a higher than average older population and as such, dementia presents a significant challenge for the health and care system locally, and its communities. The number of people with dementia in Worcestershire is set to increase to 11,257 by 2028, and 14,382 by 2038. The largest increase will be in those aged 85+, who are more likely to have increased care needs [2]

There are multiple ways in which people can receive a diagnosis of dementia in Worcestershire. Through engaging with people living with dementia and their carers we aimed to:

- Understand the information provided to people and carers on diagnosis
- Understand the experience of people with a diagnosis of Young Onset Dementia and their carers
- Understand the experience of support provided by health and social care
- Identify whether differences or inequalities exist in information and support provided across the diagnostic pathways

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[1] NICE Guidance: assessment, management and support for people living with dementia and their carers - Published: 20 June 2018 www.nice.org.uk/guidance/ng97

[2] Worcestershire Health and Wellbeing Board Dementia Joint Strategic Needs Assessment, March 2019

WHAT WE DID AND WHO WE HEARD FROM

The opportunity to participate in the project was promoted widely by HWW with an estimated reach of more than 12,700 potential contacts with the project.

We have heard the experiences of **217 people** over the course of this project through:

Survey – 131 Carers	**Survey – 38 People living with Dementia**	**7 Focus Groups**	**12 In-depth Interviews**
Female (67%), aged 65 + (85%) and White British (95%)	Female (72%), aged 65 + (67%) and White British (97%)	36 people Female (87%) Age 57-84yrs	10 Carers & 2 People with Dementia Male (66%) Age 48-91 years

Further information about who we heard from is available in the main Report

WHAT WE FOUND OUT

Diagnosis - Information and Support

'We were given a big envelope with loads of leaflets. I couldn't read all of this! I had to deal with my husband and my emotions, that was far more important. I hadn't got any capacity to take in other things – I just needed someone to talk to', Carer, Interview

'A named point of contact who is allocated to support us throughout. Someone who can advise, reassure and signpost, someone who can also advocate for us when needed. I feel very alone. I live in a constant state of anxiety and stress. Any support that came our way was time limited to 6 months. I've had enough' Carer, Survey respondent

People recognise that dementia is an individual experience, which will affect each person differently.

Information, or lack of it, was a theme that recurred frequently through our Survey and analysis of the content of our Focus Group and Interviews. These discussions revealed that providing people with the right level of information at the right time and in the right way is complex. When carers are provided with information they can feel overwhelmed, and do not always have the time or resources to be proactive and reach out for what they need.

People are often too tired/too focused on coping to follow-up or take the initiative in contacting a professional. They also don’t know the questions to ask at this early stage, or are too shocked to take in all the relevant information.

Whilst there is a significant amount of information available, not everyone is aware of the resources which exist. Awareness of the Age UK H&W Dementia Services Directory is patchy. Our Survey and qualitative work provides guidance on the sorts of topics that people would find it useful to have information about.

A flow chart, or simple pictorial representation, of what might happen at each stage of the dementia journey and the main sources of information and support was frequently requested, along with tailored information, which is specific to the person and their condition, and to where people live.

The level of information provided to people differs across the diagnostic pathways. Patients and their carers requested a clear and consistent information offer, that provides them with access to the same level of training, information and support, regardless of the diagnosis pathway they experience.

Carers did not always feel that they had the support they needed at diagnosis, and this was influenced by the pathway through which they were diagnosed. The Early Intervention Dementia Service (EIDS) was described as most often providing the right amount of information and support at diagnosis, and GPs as least often providing this. However, the EIDS intervention is short term and can lead to people feeling ‘dropped’ and ‘abandoned’ once discharged.

Of most importance to the people we spoke with was easy access to someone with knowledge and understanding about dementia to talk to as needed, who is proactive about making contact, offers objective advice and signposting (specific to their particular situation). They also want ongoing emotional support and a ‘listening ear’ that helps people to prepare for the future - someone who will walk alongside people on their dementia journey.

Age UK Herefordshire & Worcestershire Dementia Wellbeing Service

Our findings suggest that for those in receipt of the Dementia Wellbeing Service most (70%) describe the support provided as good. More people had heard of the service than were actually using it; there could be multiple reasons for this. The Service is part of the Universal Offer for people living with dementia. 69% of respondents had either not been referred to the service, or did not know if they had been referred or not. Referrals to the service vary across the diagnostic pathways, which may result in carers and people living with dementia missing out on valuable support.

The Service needs to be embedded within the local health and care system with referrals made on diagnosis, with an aim of ensuring people are linked to support and advice at the earliest opportunity.

Care Planning

'There was no joining up of services it was up to me to piece it together, it's very fragmented' Carer, Focus Group participant

Care Plans are an important tool for both professionals and people living with dementia and their carers. Our understanding is that Care Plans are part of the universal offer for people living with dementia. Despite this 83% of carers did not know if the person they cared for had a care plan or thought they did not.

Care Plans should form the basis for Annual Reviews, and can assist in ensuring that current and future needs are recognised and met.

Having a named professional or care coordinator leading on the person's care and treatment and for when the carer or patient needs advice is a recommendation within the National Dementia Care Pathway[3]. 82% of carers reported that they did not know the name of the person responsible for co-ordinating their loved one's care.

Carers wanted a more 'joined up' approach between services. There should be better communication and connectivity between services to ensure continuity of care, information, and care plans. This could help to ensure that people do not have to repeat their stories and could be facilitated through carer identification, Shared Care records and 'This is me' documentation.

Support from GP's and other Health Services

'GP doesn't know I exist. GPs are like clouds, allocated as I make an appointment. I will see a GP once then never see them again' Person with dementia, Interview

'I told the GP of the diagnosis in advance and said you will need to read up on this. What we got was a 7 minute appointment. The GP went through a checklist and that was it. We were in and out. I left feeling really disgruntled' Carer, Interview, describing their loved one's Annual Review

General Practice

General Practice is one of the pathways through which people can be diagnosed with dementia. GPs' connection to the rest of the health and care system as well as their base in the community make them well placed to take a leading role in care planning and care co-ordination for people with dementia[4]

GPs are required to maintain a register of people with a dementia diagnosis. It is important that this is kept up to date and that people living with dementia and their carers are appropriately coded on NHS records when a diagnosis is made. This would enable reasonable adjustments to be made, Annual Reviews to be programmed, and other services notified of the dementia diagnosis as appropriate.

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[3] National Collaborating Centre for Mental Health. The Dementia Care Pathway. Full implementation guidance. London: National Collaborating Centre for Mental Health; 2018.

[4] All-Party Parliamentary Group report, 2016 'Dementia rarely travels alone: Living with Dementia and other conditions'

Many carers appreciated and described the support offered by their GP practices, particularly those which had a designated dementia specialist role, such as a dementia nurse or dementia champion.

However, they also reported issues with booking appointments (including home visits); inconsistency of care; issues with medication and that some staff appeared to lack dementia awareness.

Annual Reviews carried out in a GP practice are a key part of a person care[5]. However, 45% of respondents to our carers survey were not aware of them. Of those that had received an Annual Review satisfaction varied. Carers reported that they felt the Review could be a ‘tick box’ exercise and a missed opportunity for themselves and their loved one to access much needed support. For example, carers did not always feel able to discuss their own needs or to access input around medication or coping strategies.

Understanding individuals’ needs and preferences and providing person-centred care through regular review should be a key priority. Reviews which follow the D.E.M.E.N.T.I.A. framework[6] have the potential to offer significant benefits to people living with dementia and their carers, and could address some of the issues about lack of care planning, support and co-ordination of services raised by carers through this work. At present however we cannot be confident that this is the case.

Our observation, from both the quantitative and qualitative work that we have undertaken, is that the understanding and support provided by GP practices is inconsistent and varies by practice, creating a ‘postcode lottery’ for people living with dementia and their carers.

Other Health Services

People living with dementia and their carers want the same access to health care as any citizen, but delivered with a recognition of the additional challenges which dementia can bring. For the Integrated Care System this means providing personalised care, which wraps around the person and their loved ones, and recognises the specifics of their circumstances.

For some carers the Admiral Nurse is the first point of call when help or support is required. The service was described by some as ‘brilliant’ and a ‘lifeline’. Conversely we heard from Carers who had contacted the service but had not received the support they hoped for. We appreciate that responses from services are likely to be based on an assessment of individual circumstances, nevertheless from a carers’ perspective a clear description of the assessment process and the service offer may be useful.

Although this was not a particular focus of our work carers also described their experience of hospital settings. Some had an excellent experience, whilst others

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[5] Annual Reviews are a component of the 2023/24 Quality Outcomes Framework – **Ongoing management** DEM004. The percentage of patients diagnosed with dementia whose care plan has been reviewed in the preceding 12 months

[6] D.E.M.E.N.T.I.A. framework set out in NHS England Dementia: Good personalised care and support planning guide, 2020

felt that some staff do not always have the time, skills or knowledge to deal with patients living with dementia.

Some carers wanted more information about clinical trials but were not always able to find this information.

We also heard of challenges to carers and people living with dementia to access services such as dentistry, eye and hearing checks, incontinence services and chiropody at home. Long waits for OT assessment were reported and Falls were not always quickly responded to.

These services are important to support people's well-being and at times, prevent hospital admission.

Our Case Study highlighted potential lessons for the System in respect of raising awareness of the link between Learning Disability and dementia, using the Learning Disability Annual review as an opportunity to look for and discuss signs and symptoms of dementia. A clear pathway is needed for people with a learning disabilities who require a dementia diagnosis and ongoing support and review through their dementia journey.

Support from Social Care Services

'If I start asking the wrong questions will it be taken the wrong way?' Carer, Focus group participant

'The relationship needs to be built to understand the individual and how their needs change over a period of time.' Carer, Survey respondent

Dementia is a progressive disease and over time people living with dementia and their carers may need support to maintain their independence at home or assistance to plan for the future.

Not everyone we spoke with was aware of the role of Worcestershire County Council Adult Social Care Services (ASC), their legal responsibilities or what they could offer to people by way of information, advice and support. Some carers were concerned that approaching ASC may result in their loved one being taken away from them or the situation escalating beyond the carer's control. A clear description of the role of ASC may alleviate this situation.

Of those who had contacted ASC (n64) the most frequent reasons were for support at home, for advice and information and for support in a crisis situation.

We heard positive comments about support received through ASC, and in particular a consistent allocated social worker was valued.

Of those receiving a service where ASC contributed to the cost the majority were satisfied with the quality of care provided. We asked only those who received a funded service how far they agreed or disagreed with a series of statements about the quality of care services. Respondents most frequently agreed that they were satisfied with the quality of the support, which was reliable and responsive to concerns. People were less confident they could get the response they required in a crisis situation

Other issues included frequent changes of social worker, and an apparent lack of understanding by social care workers about dementia. About 1 in 3 carers who receive a service funded by WCC felt that their needs as a carer were not understood by social care workers.

People who were self-funding (i.e. had savings above a financial threshold) felt particularly unsupported. Most self-funding carers reported they would have liked more support from Adult Social Care to organise care for their loved one.

We asked all Carer survey respondents, whether or not they had contacted ASC, about what care services they were using. We received comments about domiciliary care (reliability and consistency of care were greatly valued), respite and replacement care (carers had not always been able to find respite care that met their own and their loved ones' needs and which was flexible and affordable), day care services and residential care settings.

Support in the community for People Living with Dementia

'It saved my life, I thought I was going insane' Carer, Focus Group participant

Through focus groups and interviews, we heard how much people valued the support provided to them through local (District based) Age UK groups and activities, and by other local organisations and faith-based groups who are supporting carers and people living with dementia. Carers also praised the volunteers who ran or supported these activities.

These groups and organisations provided valuable opportunities for carers to find vital peer support and for their loved ones to continue to enjoy activities and relationships which are important to them.

Barriers to access included transport to activities, the appropriateness of the activity for the individual, timing (particularly a lack of activities in the evenings and weekends) and cost.

An identified gap in services was community support at the later stages of dementia, when some community-based services were no longer suitable for the person living with dementia due to changes in their behaviour or personal needs.

People also wanted one to one support and befriending services suitable for people unable to access community facilities.

There may be scope to better educate the public in general about dementia, and to further encourage communities to become dementia friendly.

Young Onset Dementia

'We were struggling to get incapacity benefits. So, then it was about, you know, trying to do the PIP and stuff like that. Luckily, I'm computer literate and have quite a senior job so I was able to put something together and word things … but yeah, it's a lot to have to take on board' Carer, Interview

Dementia is often described as 'young onset' when it is diagnosed before the age of 65. There are 122 people in Worcestershire who have received a diagnosis of young onset dementia.

The financial impact of a diagnosis at working age was significant and we heard that eligibility for benefits can vary according to age, therefore it is important that consistent and accurate advice is provided, and support is readily available to complete benefit applications.

Amongst the people who responded to our survey and those we spoke to; it is evident that knowledge of the Dementia Wellbeing Service is low and that referrals to it are even lower. This is a concern considering the additional needs and challenges carers of people with a diagnosis of Young Onset Dementia face.

The need for more age specific provision was evident for the benefit of both the person with a diagnosis and the person caring for them. The opportunity for peer support to develop is created via organised activities. We heard from carers how they often learned more from other carers than from any agency. Peer support was also identified as a key component in supporting the mental health of carers.

It is recognised that this community of people is a small proportion of Worcestershire's population, which may make justifying funding more challenging. However, the acuity of need makes it apparent that there is a real gap in provision. An opportunity exists to explore how some groups have created an inclusive provision for all ages.

Support For Carers

'When you've got somebody with dementia, then everything is on your shoulders.' Carer, Interview

'An understanding from all departments that caring can be extremely stressful, frustrating and exhausting and it's not a 9 – 5 role!' Carer, Survey respondent

Carers may experience poor physical and mental health and also may have unmet care needs themselves. There is mounting evidence that unpaid care should be considered a social determinant of health.[7]

The role of being an unpaid carer of someone living with dementia is a complex and demanding one, for many it is a 24/7 job, and carers feel they need support along the way. Many carers emphasised that the situation they were in was unknown, new to them and frequently challenging. They needed information, training, support, reassurance and sometimes, time to themselves and a break from it all.

Carers highlighted the challenges they face trying to balance caring and a working life.

Not everyone acknowledged or accepted the description of themselves as a Carer. Some felt that professionals and services made this assumption, sometimes to the detriment of the Carer.

Only 10% of Carer Survey respondents told us that they felt supported in their caring role.

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[7] Caring as a social determinant of health: review of evidence - GOV.UK (www.gov.uk)

The Worcestershire Association of Carers (WAC) provides a range of services for unpaid carers across Worcestershire. These include the Worcestershire Carers Hub. The Hub is funded by Worcestershire County Council. 65% of respondents had heard of WAC and 35% had been in contact with the organisation. Of those who had been in contact with WAC satisfaction was varied, 62% reported that they were neither satisfied or dissatisfied with the support received, 26% were satisfied and 12% were dissatisfied.

Where provided, proactive support was welcomed, however some carers we spoke with reported a lack of awareness of the range of the services on offer or difficulties in accessing them. This was sometimes because they were unable to find replacement care.

Most carers (67%) had not been referred to WAC or did not know if they had been referred or not. It would appear that there is scope for NHS, ASC and other organisations to play a more proactive role in referring Carers to WAC.

Most Carer survey respondents (68%) were not aware of their entitlement to a Carers Needs Assessment, and only 8% have had such an assessment. Providing information about WAC and the Carers Needs Assessment is part of the universal service offer. This suggests that there is a need to promote this entitlement and highlight to them the potential benefits that this could bring.

CONCLUSION

A diagnosis of dementia is life changing for the person living with the condition and their family and friends.

As a County with a higher than average older population the challenge which dementia presents for the individual, their carers, our communities and for the health and care system locally is set to increase.

Through this work we have heard of both the positive aspects of care and support provided to people living with dementia and their loved ones and also some of the struggles and issues encountered.

There is a lack of consistency in the information and support that people living with dementia and their carers receive and this is influenced by the pathway through which they are diagnosed. They are not routinely offered referral to key services such as the Dementia Wellbeing Service and Worcestershire Association of Carers.

There is a lack of awareness of Care Plans and Annual Reviews. Implementation of these is patchy, yet they offer the potential to address some of the needs so clearly expressed by the voices that we have heard through our work.

There is some lack of understanding of the role of Adult Social Care, and how it can be of benefit in understanding and meeting people’s existing needs and planning for the future. Carers require support in navigating an unfamiliar care system regardless of their financial circumstances.

People need health and care services where staff understand the challenges that dementia presents, and services will make reasonable adjustments to accommodate them.

Activities and support in the community is highly valued, yet barriers to access exist which need to be addressed.

For many caring is a 24/7 role, which can significantly impact on carers own quality of life. Carers should not have to fight, chase or push to uncover care and support that should be available to them. Nor should they be further burdened by the difficulties people have reported navigating the system of health and care.

It is clear that while each person and their carer's needs, experiences, and preferences are unique, they need to know that our Integrated Care System is there for them, providing regular, proactive advice and support when needed, throughout this unpredictable journey.

As such it is critical that across our Integrated Care System, the issues that we have identified in this Report are addressed.

RECOMMENDATIONS

Diagnosis - information and support

1. Ensure that diagnosis is the key to accessing a clear pathway of consistent support for people living with dementia and their carers
2. Ensure those who choose not to access a diagnosis are not denied information, advice and access to services.
3. Introduce an 'opt out' approach for referrals to the Dementia Wellbeing Service and Worcestershire Association of Carers
4. Consider how the EIDS service manages discharge, and whether there is potential for people to move into and out of the service over time as needs change, to prevent feelings of invisibility and abandonment.
5. Ensure that people have access to a named individual contact who is knowledgeable about dementia and can provide proactive and ongoing information, advice, signposting and emotional support.
6. Develop a clear and consistent information and support offer at diagnosis, which provides people living with dementia and their carers with access to the same level of training, information and support, regardless of which pathway they are diagnosed through.
7. Consider how diagnosis, reviews, local community spaces and activities, health, care and voluntary sector settings, and online opportunities can be maximised to better promote the wide range of resources (particularly local resources) which are available to inform & support people living with dementia.
8. Ensure that information is accessible, and available in a range of formats to meet individual need including for people with additional communication needs or whose first language is not English
9. Develop a pictorial representation of what might happen at each stage of the dementia journey and identifies the main sources of information and support, including practical and financial information and advice

Age UK Herefordshire & Worcestershire (Age UK H&W) Dementia Wellbeing Service

10. Ensure that all diagnostic pathways are aware of the Dementia Wellbeing Service, and introduce an ‘opt out’ approach to referrals to the service.
11. Ensure that the Service is sufficiently resourced to deal with demand.
12. Ensure that the Service is able to offer a timely response and consistent offer to the people who contact it.
13. Develop a plan to increase the visibility of the service across relevant parts of the NHS, Adult Social Care (Front Door & ASC Teams) as well as Voluntary, Community and Social Enterprise organisations including dementia groups.

Care Planning

14. Provide all people living with dementia with a key worker or meaningful contact for support, recognising continuity is important to people, over the long term (see Recommendation 5)
15. Ensure that every person who is diagnosed with dementia has a personalised Care Plan, which is developed alongside an appropriately qualified practitioner.
16. Ensure the Plan discusses what matters most to the person living with dementia, considers the wider family in care planning, pays attention to their own and their carers’ needs, including their wider health and wellbeing.
17. Give families a copy of the Care Plan so they can refer back to it and share plans with other health and care services.
18. Monitor how this is being implemented.
19. Consider how connectivity between services to ensure continuity of care, information, and care plans can be facilitated and developed, including through the use of the Shared Care Record.

Support from GP’s and Other Health Services

GPs

20. Ensure that the diagnosis of dementia is added to the person’s medical record and GP dementia register.
21. As a minimum, ensure carers are identified and recorded on a GP practice carer register, along with a contingency plan - should they be unable to provide care
22. Consider how to build on people’s positive experience of dementia-specific roles in primary care, and ensure equity in access across the County. This could include consideration of how social prescribers could support people living with dementia and their carers.
23. Ask GP Surgeries to identify how they will make reasonable adjustments to ensure easy and consistent access to care and services within the practice for people living with dementia and their carers
24. Provide all people living with dementia with an annual review by an appropriately qualified practitioner, ensuring more frequent reviews for those with greater need – as identified through effective care planning.
25. Reviews should follow the D.E.M.E.N.T.I.A. framework set out in the 2023/24 Quality Outcomes Framework; addressing the needs of carers as well as those

living with dementia and signposting to other services and support, as appropriate.

Other Health Services

26. Raise awareness, and provide education and training, among health and care staff to ensure they can recognise the symptoms of dementia and know who is at risk.
27. Ensure health and care staff know how to recognise and identify carers and can help carers to recognise their caring role.
28. Consider what information, education, training and skills health and care staff may need to ensure that they can appropriately meet the needs of people living with dementia and their carers across a wide range of health and care settings.
29. Ensure that all health and care services make reasonable adjustments to meet the needs of people living with dementia and their carers so that services are accessible to them, including in the home setting where appropriate.
30. Ensure people are aware of the Admiral Nurse service offer and are clear about how to access this.
31. Ensure that health and care staff working with people with a learning disability are aware of the link between learning disability and dementia
32. Ensure that signs and symptoms of dementia are considered as part of the Annual Learning Disability Review
33. Set an age at which a baseline assessment is established, with which future assessments can be compared
34. Ensure there is a clear pathway for diagnosis, support and review of people with a Learning Disability who are diagnosed with dementia.

Support From Adult Social Care Services

35. Promote awareness of Adult Social Care and people's entitlements under the Care Act 2014 using a range of formats and channels (see Recommendations 7 & 8)
36. Explain the role of Adult Social Care and how the journey through Adult Social Care works using a range of formats and channels.
37. Ensure people who are self-funding feel supported, recognising that finding and organising high quality care will be unfamiliar to many people who contact the service.
38. Ensure that people in receipt of Adult Social Care services have access to an allocated social worker.
39. Ensure that Adult Front Door and Social Care staff have the necessary information, skills and training to engage effectively with people living with dementia and with their carers.
40. The Integrated Care System (ICS) should ensure that there are a range of opportunities for respite which includes helping carers to take a break for a few hours in the day or to sleep at night, as well as residential respite care for longer periods of time, and ensure that carers are aware of these opportunities.
41. The ICS to consider how the feedback we received about care services can be utilised effectively within the system.

Support In the Community for People Living with Dementia

The Integrated Care System should:

42. Continue and expand support groups and activities through non-statutory services in areas where provision is limited, including in the evenings and at weekends.
43. Increase opportunities for people living with advanced-stage dementia, who may also have physical health needs, to engage in meaningful activities.
44. Ensure that one to one and befriending support is available to those who need it
45. Consider how barriers to access such as transport to activities, the appropriateness of the activity for the individual, timing (particularly a lack of activities in the evenings and weekends) and cost can be addressed.
46. Support the development of more dementia-friendly or dementia inclusive activities and communities and consider what resources, information and advice may be required to do this

Young Onset Dementia

47. Ensure that consistent and accurate information and advice is provided, to people with young onset dementia and their carers, including financial advice and practical support where required (e.g. to complete benefit applications)
48. Introduce an ‘opt out approach for referrals to the Dementia Wellbeing Service and Worcestershire Association of Carers.
49. Consider how existing support groups might develop a more inclusive approach to accommodate all ages.

Support for Carers

50. On diagnosis make Carers aware of Worcestershire Association of Carers and introduce an ‘opt out’ approach to referrals to the service.
51. Ensure that the Service is sufficiently resourced to deal with demand.
52. Carers should be informed about the Carer’s Needs Assessment, and how this might be of benefit to them.
53. Develop opportunities for peer support, particularly for younger, working carers.