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together in dementia everyday

Alzheimer's Society
United Against Dementia

Submission to EHRC Inquiry into challenging decisions about adult social care

Life Story Network/tide and Alzheimer's Society have joined forces to present views for this consultation based on feedback from people affected by dementia who have encountered our services.

Social care is a vehicle which can provide opportunities for people affected by dementia (people who have received a diagnosis and those people who are supporting them) to doing what matters to them and to maintaining a positive sense of identity. We write from a position of belief that the role of social care, when organised well, enables people affected by dementia to remain in control of their support and lives as much as is possible within their individual contexts. That social care is a means to an end in enabling people to continue their lives that are meaningful.

It is frustrating to hear of experiences that run counter to basic human rights or the now, well established, Dementia Statements, that reflect the things that people living with dementia and their carers say are essential to their quality of life. This Inquiry is a response to the recognition that services do not always meet the standards required of them, and we are pleased to be able to contribute to it. Our recommendations are intended to provide achievable solutions that can support people affected by dementia to be involved meaningfully and effectively in determining their own individual support packages.

Methodology

In order to supplement our existing knowledge of the experiences of challenging local authority decisions from the two organisations, tide undertook a short survey of carers of people living with dementia. To fit into the short timescale of the Inquiry, we invited unpaid carers of people living with dementia, both former and current, to share their views with us over a two week period. We received 27 responses and have collated these in relation to the Inquiry questions.

Permission was given by respondents to submit these responses on their behalf. Quotes, unless attributed otherwise, are from the tide survey for the Inquiry.

Q1 & 2

What were the reasons why you were unhappy with the decision?

The bulk of respondents (over half) ticked 'I did not agree with how or where the council offered to meet my needs', followed by over one third feeling that the assessment did not consider all of their needs.

Themes of the issues raised by respondents to our survey:

- Quality of advice and information was poor
- Not being able to contact the right people when needed
- Lack of consultation and feeling they weren't listened to
- Insufficient or inappropriate care and support offered to meet needs: lack of professionalism
- Services offered did not meet carer needs
- Impact on health and mental health

The range of difficulties quoted provided an overwhelming sense of the struggle people so often experienced to access services, to feel listened to and then be able to draw on sufficient resources in their community to meet their needs.

Quality of advice and information was poor

Post-diagnostic support and care for people living with dementia and their unpaid carers appears to be lacking, as Alzheimer's Society's *From Diagnosis to End of Life* found that provision can be 'variable and inappropriate'.[i] Unpublished data from the IDEAL study[ii] shows that 70% of people with dementia and 71% of carers haven't taken part in any intervention to help with their condition.[iii] The respondents were often left floundering as to who to approach and where to get information, including worryingly, in a crisis.

Lack of information also hampers the ability of carers to challenge decisions or to fully participate when they are uncertain of their rights and those of the person living with dementia. It can really put the carer at a disadvantage.

'I was not given all options [as carer], only told about care home or personal care. Since I have had to find out all information myself and options for Alzheimer's is a fight to get appropriate care…, . Very much keeping options close to [their] chest and not being open. I had to fight to change care manager because of this'

The above quote highlights several issues that were raised about not only what was being offered but also the quality of advice and information given.

'..[I] wasn't allowed to care for my husband with severe dementia in hospital after which he rapidly deteriorated. I was not informed that physiotherapy wasn't given despite it being an essential need. I was only given certain information when i asked for it'

‘What service users are saying: They are not listened to by Adult Social Services. On one occasion the worker did not even read that the person had dementia! Very slow process. Adult Social care did not care’

‘I also had to call for a meeting with the care team involved in his care plan (in Jan/Feb 2020) to find out the information regarding plans for his future - this despite the fact that the Council’s own policies state quite clearly that I (and my children - all of us with P.o.A. for my husband) should have been included in discussions and kept informed of decisions at all times - we were not’

‘When my husband was diagnosed with Vascular Dementia I was told there was no treatment and we just had to learn to live with it. It was 9 months before I received any support and then only in drips and drabs. A folder containing all relevant organisations and what was available in the way of support should have been given at the diagnosis. I was left floundering and had to search the internet for information.’

Lack of appropriateness in service design can cause barriers for people from many groups, including people from Black, Asian and Minority Ethnic (BAME) communities, and people from the Lesbian, Gay, Bisexual and Transgender (LGBT) community. It’s vital that we look at how to make activities and services more inclusive. People from BAME communities may face additional barriers relating to language and culture. For example, some older BAME people may be less likely to speak English or use English as their dementia progresses. The provision of interventions must be reviewed and made more appropriate and tailored. It must consider age, ethnicity, gender and sexual orientation, and reflect the diversity of our society. [iv] A 2020 study surveying dementia commissioners revealed that few areas reported providing dementia health services specifically for BAME populations.[v]

One BAME carer highlighted how information can get lost in translation and an added stress for family members can be having to interpret as well as ensuring that the all professionals in the system are getting the same information. The stress increases when families live apart.

People diagnosed with dementia need to have access to follow-up opportunities to discuss their diagnosis and this needs to be embedded within the local pathway. For example, this could be delivered through follow up within primary care by a GP, specialist nurse, dementia adviser, or through memory services. There must be opportunities to step up care when more support is needed. [vi]

A lack of familiarity with the system, exacerbated by a different understanding of the symptoms of dementia creates problems for BAME elders navigating the dementia pathway. This then leads to an under-utilisation of services by BAME people affected by dementia, which in turn can contribute to a lack of development of measures to ensure equal and fair access for all.

Not being able to contact the right people when needed

Caring for a person living with dementia can be stressful and time consuming and not knowing who to contact is frustrating. Recommending access to care coordinators could significantly help people navigate the complexity of the health and social care system to get the right care and support. Part of the post diagnostic package needs to include information about services and contacts. The lack of single point of access as prescribed in NICE guidelines was clearly apparent in the cases described in the survey.

‘I have had to initiate or chase every step of the process up - no two way flow of information-and very difficult to contact people’

‘Assessment was done via an agency worker who did not understand my situation or the extent of my wife’s illness. I had four different Social Service contacts in 12 months. I was never told when the replacement would be which caused me more stress chasing shadows’

‘I had a phone call from the social worker saying my Mum’s case was being closed. I had such a struggle to get an appointed social worker. (I) couldn’t believe, especially in these circumstances, that support has been withdrawn’ (carer, tide 2020, The Experiences of Carers of People Living with dementia during the Covid-19 Pandemic)[vii]

It is important that all people with a dementia diagnosis should have a named care coordinator. For example, this could be allocated during the initial post-diagnostic support meeting with the memory service but could be reviewed within primary care.[viii]

Lack of consultation and feeling that they weren’t listened to

NICE clinical guidance for people living with dementia and their carers sets out clear guidelines on involvement of the person and their family carers in care planning and ensuring they understand their rights. In the survey we were made aware of many examples, as shown in this response, where carers and the person living with dementia were not seen as care partners in any meaningful way.

Recognising the importance of relationships to health and wellbeing is one of the fundamental principles of social care and care plans, including building or strengthening relationships with loved ones and family members.[ix] Training packages for staff such as the NIDUS homecare staff project (New Interventions for Independence in Dementia)[x] reflect that family carers are vital, and need to be involved as a partner in care planning.

‘I was not consulted in decision made to transfer to other hospital instead of discharge home..’

‘I was not informed about the possibility of direct payments/self directed support’

Considering and taking into account the views of service users and carers is critical to person-centred care and support. Local authorities need to adopt a co-production approach working on the assumption that the person themselves or the carer supporting them knows best about their own outcomes, goals and wellbeing. This approach starting from initial assessment to identify preventative measures and respond to current and future needs as a shared endeavour seems to have been lacking for our respondents.

‘..I and my relative did not have an opportunity to discuss the care plan. A care plan was not supplied to us. The care company it was allocated to told us what they had been asked to do’

Making It Real,[xi] the Think Local, Act Personal (TLAP) framework for personalised care and support calls attention to an expectation that local authorities will “*view those of us in receipt of support or carers providing support, as equal partners. We continue to be experts in our own care and support whatever the circumstance”.* tide made this point firmly in the L4DC (Law for Dementia Carers Covid-19)[xii] report underlining the need to continue to operate from an ethical framework despite Care Act (2014) easements introduced during the Covid-19 pandemic under the Coronavirus Act (2020 and. Alzheimer’s Society’s briefing for local authorities reflected the need for councils to continue to meet the needs of people with dementia and the importance of councils making every effort to meet their duties including continuing to carry out proportionate, person-centred care planning.[xiii]

‘At mum’s initial assessment, I felt my opinions were ignored. This led to a delay in diagnosis and increased stress on me as the carer’

Insufficient or inappropriate care and support offered to meet needs; lack of professionalism

Numerous examples of poor care or lack of support to meet individual needs and prevent mental ill health for carers were shared with us suggesting that the commitments of the PM’s Challenge on Dementia 2020 to ‘*get the safest, best care in hospital, when they receive care at home and in every care setting*’[xiv] were clearly far from being achieved for many people.

In one situation, the unpaid carer had asked for a break but wanted to be able to spend this time alone in her own home, so was offered support for the person they care for in care home or day care setting. However, because the person was attending day care there was a cost to it, whereas if the person living with dementia had been cared for at home, there would have not been a cost. This highlighted one way in which funding policies can hamper appropriate care.

‘I was awarded 4 hrs per week ‘carer break’ but wanted my break alone in my home and my caree minded offsite at a local day centre or at a local care home that offered day sitting. The council said this was a benefit to caree and that he should pay for this’

The quality of paid care staff can be variable and one carer said:

‘I enquired to see if I could get a direct payment to enable me to employ a private specialised Dementia carer for my wife, because the Social Services were supplying untrained carers through an agency, I was told this was not possible’.

It is important that care staff supporting people with dementia have sufficient training in dementia and personalised care, to enable them to provide good quality care that meets people’s needs. [xv] Data suggests that only 44% of all workers had training in the category of ‘dementia’ recorded – however this does not indicate the level of this training, so may only include basic awareness rather than skills in direct care.[xvi]

The lack of availability of care staff with appropriate language skills was highlighted as causing problems especially for long distance family care-givers.

Several respondents referred to a lack of professionalism at times, ranging from constant changes of social worker, to lack of maintaining contact and lack of information and even wrong information.

Several examples were given of inappropriate and unprofessional behaviour:
‘..Additionally when an assessment was made regarding paying for my husband’s care I had to instruct a solicitor to act on my behalf since the council unilaterally made a decision regarding the state of my marriage and advised [by council staff] that “it was a pity I had not divorced since then at least I would have had 50% now I would get nothing”’

‘The unprofessional opinions and lack of the correct knowledge to so-called professionals within social services was a disgrace’

And in short from one carer
‘I wish this was not my life. I feel my life slipping away. Worry about what the future holds’ (tide, 2021, Crowded Isolation and `loneliness: A Perspective from Carers of People Living with dementia)[xvii]

Services offered did not meet carer needs
The struggles that carers told us about indicated many deficiencies in the way that services interacted with them. Not least in the lack of education and skills training that, had they had the opportunity to, could have prevented some of the time consuming attempts to get the right support or even speak to the right person. Having advice and information about how to look after their own physical and mental health, about planning for the future, about developing personalised strategies for coping should all be available locally (NICE QS184)[xviii], but the feedback we gained suggested that this is far from universal.

‘I work full time. All of the formal support for carers. I.e. post diagnostic support, was during the day. I was in work’

‘We were offered their maximum number of hours they would give. It was 2hrs per day in 4 x ½ hours sessions. My needs or preparedness to care was not discussed.’

Impact on health and mental health
Caring for a family member living with dementia can be rewarding. However, caring for people living with dementia can be particularly challenging, due to the complex, unpredictable and progressive nature of dementia. This is particularly so if carers feel that their role as care partner is not being recognised by the local authority.

Alzheimer’s Research UK estimate that 48.4% of carers have a long-standing illness or disability. (Alzheimer’s Research UK, 2018. Dementia Statistics Hub)[xix]

‘*Carers often feel the profound effect the role can have on their own lifestyle – spending long hours providing care, juggling their own needs with those of the person they are caring for, and forfeiting their social time. As a result, carers of people with dementia are more likely to experience stress and depression’ (Dr Jane Fossey in Alzheimer’s Society (2018) Carers for people with dementia struggling in silence)*[xx]

The effect of some of the decisions made by services had a negative effect on the carer:

‘My mental health took a hammering and the council offered no support’.

Another response was simply *’depressed’.*

The unrelenting nature of caring for someone whose behaviour can change with their mood, is continuously evolving over time. Caring for someone who needs support yet wants to remain independent can be a heavy load and however determined a carer is to carry on, their sense of duty and/or compassion is a lonely business. Having the opportunity to obtain timely, accessible and appropriate care or respite breaks can therefore be of benefit to not only their mental health and well-being but also that of the person they are caring for.

In talking about her frustrating experiences of trying to secure appropriate support for her mother, one respondent said *‘I had to go down the road of emergency respite as I was beyond coping’.* This approach shows that lack of appropriate breaks and support as part of a care plan only increases demand on council services further down the path as people reach crisis point.

“The ongoing demands of caring for someone with dementia & other health needs which can be individually demanding, taken together becomes a real juggling act. The unpredictability of dementia, the life-threatening crises it can throw up, can-does- take its toll on us physically, mentally, spiritually’ (carer, tide 2020, The Experiences of Carers of People Living with dementia during the Covid-19 Pandemic)

‘I can feel that I am slowly getting to the end of my tether & finding it hard to stay patient (carer, tide 2020, The Experiences of Carers of People Living with dementia during the Covid-19 Pandemic)

Q3 & 4

Did anybody from the council tell you that you have right to challenge any decisions that were made about your support?

Three quarters of people who responded to our survey responded ‘No’ and as a consequence these people were not told how they could challenge the decision.

This is contrary to NICE Guideline (NGi97)[xxi] on dementia - ‘*It is essential that informal carers have good support to enable them to manage the stresses and demands of caregiving and to fulfil their role’*. The Care Act (2014) makes provision for carers to be able to have an assessment in their own right where their caring role impacts upon their wellbeing. Not being aware of one’s rights, particularly being able to challenge decisions, contributes significantly to powerlessness in the face of authority, of lacking the ability to exercise choice and control as an equal care partner.[xxii]

Q5

How easy was it to challenge the decision, e.g. make a complaint, ask for a review or lodge an appeal?

Over half responded that they felt that it was difficult, followed by several people saying that it took a bit of effort and an equal number saying that they found it so difficult that they gave up. One respondent only saying that it was easy. One damning response was:

‘I didn't have a positive experience on any challenges in 6 years’.

Q6, 7 & 8

Did you tell anybody that you were unhappy with your local council's decision(s) about your support?

The vast majority of people said that they had told someone about their unhappiness about care and support decisions - mostly people had told their friends or family members. ‘*One of the biggest fears reported by families was the feeling of no longer being involved or part of their relatives car*e’ (tide 2021, Restoring Relationships: the Recovery of Love, Connection and Family). This quote was in relation to the effect of the pandemic on contact with care homes residents, however resonates with what we have heard from carers previously.

Approximately one third of people had spoken to someone from the local council about their dissatisfaction.

Responses to these questions was very much in line with earlier responses where people had outlined the difficulties that they had in achieving the right care for either themselves or the person living with dementia.

Tardiness of services to effect any change featured in the list of issues addressed in Q8

‘Had to get advocacy after months went and asked doctor to change ineffectual care manager it happened however it took 10 months’.

‘Waiting on response. I have met some members of staff in both hospitals who agree the support and proper assessment has been lacking’

For some though, no positive outcome was forthcoming:

‘She called the council to try to get an explanation and also checked with carers service that this was correct but also came up against a brick wall’

‘Alzheimer’s Society - I work for them, what a lot of complaints about the slowness, worker engagement and results of assessments’

‘Listened but did nothing’

‘Nothing more to say as I couldn’t get anyone in authority to help’

‘Sympathetic but unable to offer help’

One person described how they had used a solicitor to take matters further which had clearly given some hope, but of course this option is not open to everyone for financial reasons.

‘My solicitor was amazing as was a work colleague. Between us we gathered sufficient information and case study to show that the Council's approach was incorrect. The Council was not helpful - especially when advising they could take me to court to get a decision made to sell my house and leave me homeless’,

Recommendations

What feedback from carers of people with dementia tells us is that the current arrangements for accessing social care are cumbersome and not designed to make it easy for people affected by dementia to enter into a constructive dialogue about the right level and type of support for them as individuals to draw on to help them live well with their dementia. Dissatisfaction is fostered early on in contact between people who draw on services to support them to live well, and adult social care providers and commissioners. For carers in particular, not being treated as an equal partner in care causes additional stresses and frustrations in an already difficult caring role.

Whilst the pandemic has clearly had an impact on managing caring responsibilities and the system as a whole, they have merely highlighted existing difficulties. Increasingly social care staff have been expected to focus on 'time & task' and work in a crude task-centred way that ensures case closure once the task is complete. From a service delivery point of view this enables a more rapid throughput of work (cases) but does not lend itself to the building of longer term partnerships which can both be preventative and able to respond more effectively in a crisis.

A more expansive vision for social care should

- place greater emphasis on personal agency, choice and control, built on the underlying assumption that people are ultimately best placed to make decisions on their care, support and wellbeing
- adoption of a co-production approach by local authorities to ensure that support assessment and planning is a shared endeavour
- A belief that social care and care and support services are not a destination in themselves but should be capable of supporting people to find purpose, meaning and connection in their daily lives.[xxiii] Think Local Act Person's *Making it Real* framework states that '*personalisation is rooted in the belief that people want to have a life not a service*'
- Greater cultural awareness and openness to understanding the perspective of people from under-served communities
- The need for automatic access to local community interpreting and translation services, including braille, that are not limited by cost
- Improved training packages for care and support staff
- Ensure that unpaid carers know their rights and eligibility criteria under Care Act (2014)
- Carers of people living with dementia are identified by the health and social care system with a clear carer support pathway, including key worker at point of diagnosis

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[i] Alzheimer’s Society (2020) *From Diagnosis to End of Life*, available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life

[ii] Clare, L et al (2014). Improving the experience of dementia and enhancing active life - living well with dementia: study protocol for the IDEAL study, Health and Quality of Life Outcomes. 12(1): 164-179.

[iii] Alzheimer’s Society (2020) *From Diagnosis to End of Life*, available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life

[iv] Alzheimer’s Society (2020) *From Diagnosis to End of Life*, available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life

[v] Frost, R et al (2020). Mapping post-diagnostic dementia care in England: an e-survey, Journal of Integrated Care [Online]. Available at: www.emerald.com/insight/content/doi/10.1108/JICA-02-2020-0005/full/html [Accessed 17 August 2020].

[vi] Alzheimer’s Society (2020) *From Diagnosis to End of Life*, available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life

[vii] *tide 2020, The Experiences of Carers of People Living with dementia during the Covid-19 Pandemic https://www.tide.uk.net/resources/the-carers-experience/*

[viii] Alzheimer’s Society (2020) *From Diagnosis to End of Life*, available at: https://www.alzheimers.org.uk/about-us/policy-and-influencing/from-diagnosis-to-end-of-life

[ix] Alzheimer’s Society (2020) *A Future for Personalised Care*, available at: https://www.alzheimers.org.uk/sites/default/files/2021-03/A%20Future%20for%20Personalised%20Care.pdf

[x] UCL, *NIDUS,* available at: http://www.ucl.ac.uk/psychiatry/research/mental-health-neuroscience-department/nidus/about-nidus-study

[xi] Think local act personal (2018) *Making it real*, available at: https://www.thinklocalactpersonal.org.uk/makingitreal/about/making-it-real-documents/

[xii] tide, Life Story Network & Making Space (2020) Law for Dementia Carers (L4DC) Covid-19 Report. Impact of the Coronavirus Act (2020) and legal issues on Carers of People with Dementia https://www.tide.uk.net/resources/law-4-dementia-carers/

[xiii] Alzheimer’s Society (2020) Alzheimer’s Society makes recommendations for local authorities adopting Care Act easements, available at: https://www.alzheimers.org.uk/news/2020-05-07/alzheimers-society-recommendations-local-authorities-care-act-easements

[xiv] Challenge on Dementia (2015), https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020

[xv] Alzheimer’s Society (2020) *A Future for Personalised Care*, available at: https://www.alzheimers.org.uk/sites/default/files/2021-03/A%20Future%20for%20Personalised%20Care.pdf

[xvi] Skills for Care (2020) *The State of the adult social care sector and workforce in England 2020*, available at: https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2020.pdf

[xvii] tide, 2021, *Crowded Isolation and `loneliness: A Perspective from Carers of People Living with dementia* https://www.tide.uk.net/resources/crowded-isolation-and-loneliness/

[xviii] NICE (2019) Dementia: Quality Standard, https://www.nice.org.uk/guidance/qs184

[xix] (Alzheimer’s Research UK (2018) Dementia Statistics Hub

[xx] Alzheimer’s Society (2018) Carers for people with dementia struggling in silence https://www.alzheimers.org.uk/news/2018-06-22/carers-people-dementia-struggling-silence

[xxi] NICE (2018) Dementia: assessment, management and support for people living with dementia and their carers, https://www.nice.org.uk/guidance/ng97

[xxii] SCIE, Eligibility under the Care Act 2014 https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/criteria

[xxiii] Alzheimer’s Society (2020) *A Future for Personalised Care*, available at: https://www.alzheimers.org.uk/sites/default/files/2021-03/A%20Future%20for%20Personalised%20Care.pdf