

Katie Hanson
Consumer Affairs
Second floor
Ofcom
Riverside House
2A Southwark Bridge Road
London
SE1 9HA

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Dear Ms Hanson,

Alzheimer's Society response to Improving access to electronic communications services for disabled people

Summary

- Alzheimer's Society believes the proposed changes to communications services are positive and would be of benefit to people with dementia.
- Alzheimer's Society supports the proposal to allow third parties to report a fault on a telephone line of a person with dementia.
- The telephone can be an important tool for people with dementia to maintain contact with friends and relatives; however, very few people with dementia use digital communications.
- Many people with dementia use telecare services and rely on a functioning telephone line, even if their cognitive abilities mean that they are not able to use the telephone for communication.
- Communications providers need to have an awareness and understanding of dementia to ensure staff are able to answer enquiries from people with dementia.

About Alzheimer's Society

Alzheimer's Society is the UK's leading support services and research charity for people with dementia and those who care for them. It works across England, Wales and Northern Ireland. The Society provides information and support for people with all forms of dementia and those who care for them through its publications, dementia helplines and local services. It runs quality care services, funds research, advises professionals and campaigns for improved health and social care and greater public awareness and understanding of dementia.

About dementia

The term dementia describes a set of symptoms that include loss of memory, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease. Dementia is progressive, which means that people with dementia and their carers are coping with changing abilities over time. These changes in ability include a reduction in the person's capacity to make decisions about major life events and circumstances as well as day to day decisions. Eventually they will need help with all their daily activities.

Safeguard scheme for disabled users: third party fault notification

Alzheimer's Society supports the proposal to allow third parties to report a fault on a telephone line of a person with dementia. Although Alzheimer's Society is supportive of all the other proposals, the numbers of people with dementia who would benefit from changes would be very few. This is because there only a few people with dementia who use internet services. The reasons for Alzheimer's Society's support of the safeguarding scheme are set out in the answers below.

(i) What problems (if any) do disabled users face in personally notifying communications providers of faults in their services, and with what consequences?

Recent research from Alzheimer's Society highlighted that many people with dementia have difficulties using the telephone, although some people with dementia may need the telephone line in order to use telecare services. However, if there is a fault on the line, the person with dementia may not be able to use or have access to another telephone in order to report a fault. This could be because they have difficulty in communicating or following conversations on the telephone, or the level of their cognitive impairment means that they cannot use a telephone or remember the telephone number. As a result, the person may not be able to report the fault meaning that that their telecare service does not function, or family members cannot get in touch with their relative, leading to further worry.

On the other hand, a person with dementia may attempt to report a faulty service, but because they forget personal details, the communications provider staff may not have any understanding of dementia, which could complicate the process of reporting and the problem could be left unresolved. It is for this reason that Alzheimer's Society recommends communications providers strive to become dementia friendly in line with the dementia friendly communities ambition in the Prime Minister's challenge on dementia.

(ii) What would be the benefits of relevant disabled users of the possible changes to allow third-party fault notification?

Recent research from Alzheimer's Society showed that the telephone is an important tool for overcoming feeling of social isolation and loneliness. Nearly half (46%) of people with dementia living alone who responded to a survey stated that they speak to family or friends every day on the phone. Evidence from people with dementia suggests that they look forward to regular phone calls from family or friends as this alleviates boredom and loneliness. Some people with dementia living alone live at a distance from their relatives, so they rely on the telephone to maintain contact. However, due to the nature of dementia, if the telephone line developed a fault, some people with the condition may not understand that there is a problem or be able to report it. Furthermore, it could be very difficult for a family member to establish the problem and visit the person with dementia in order to support them to report the fault. Therefore, Alzheimer's Society supports the proposal that people with dementia can nominate a third party, such as a trusted neighbour or relative, to be the contact for a communications provider if there is a fault with the customer's line.

Assistive technology, such as telecare, can promote independence for people with dementia and enables them to remain living in their own home for as long as possible. Therefore, if a person with dementia has a faulty telephone line, they could be at risk of an accident if their telecare is not working.

(iii) What barriers (if any) are there to implementing a system of third party fault notification?

There could be barriers around people with dementia having the capacity to nominate a third party who can report faults on a person with dementia's phone line, particularly if the person has no provision for lasting power of attorney. Over 60% of people with dementia never receive a formal diagnosis meaning that they are unable to make plans for their future should they lose the capacity. Alzheimer's Society recommends safeguards which ensure that a person with dementia is still able to nominate a third party to report faults, but which prevents the third party from taking advantage of the person with dementia.

Alzheimer's Society is grateful for the opportunity to respond to this consultation. If you require any further information, please contact me on the details below.

Yours sincerely,

Laura Cook
Policy Officer

Tel: 020 7423 3578

Email: laura.cook@alzheimers.org.uk