Support services: Advocacy

May 2019

May 2019 not a full specification review – addition of a safeguarding statement only. All other content last reviewed July 2012.

1 Advocacy services for people living with dementia

1.1 For most people, making their own decisions and choices is a matter of considerable importance. Being part of decision-making processes is not only where self-identity is expressed but is also an important aspect of personal freedom. This principle is at the heart of advocacy services for people living with dementia.

1.2 Mental health advocacy has been around in various forms for a significant amount of time and is an important user-led and defined service. With focus on the published and planned strategies for dementia across England[1], Northern Ireland[2] and Wales[3], services that aim to give people living with dementia greater control over the support and care they receive are being highlighted. The legislative framework also supports recognition that people with impaired capacity have the right of choice, protection and validation of their wishes and needs. There is also widespread recognition that those who sometimes have the greatest need may receive less attention from service providers (inverse care).[4] Specialist advocacy can help health and social care professionals, carers and families work with a person with dementia to redress this.

1.3 The introduction of statutory advocacy and independent mental capacity advocates (IMCAs) under the Mental Capacity Act 2005 (England and Wales) gives some people who lack capacity a right to receive support from an IMCA. The service came into effect in April 2007 in England and in October 2007 in Wales. The Mental Capacity Act 2005 makes it a legal requirement for people lacking mental capacity, including those with dementia, to have independent advocacy when there are no known relatives or close friends to speak for them. Under the act, an IMCA must be provided when decisions are being made regarding a) serious medical treatment and b) a move to other accommodation, in specified circumstances.

1.4 The need for advocacy for people with dementia, who face complex issues around social exclusion and deteriorating cognitive function, may be much broader than access to statutory services and treatment. Independent advocacy services may provide support for people to:

- make changes and take control of their life

[1] Department of Health (2009). Living well with dementia: a national dementia strategy. [online] Available at: www.dh.gov.uk [Accessed 15 July 2012]

[2] Department of Health, Social Services and Public Safety (2011). Improving dementia services in Northern Ireland: a regional strategy. [online] Available at http://www.dhsspsni.gov.uk/improving-dementia-services-in- northern-ireland-a-regional-strategy-november-2011.pdf [Accessed 23 July 2012

[3] Welsh Assembly Government (2010). National Dementia Action Plan for Wales. [online] Available at: http://wales.gov.uk/docs/dhss/consultation/090615dementiaplanen.doc [Accessed 15 July 2012]

[4] Bruce E, Surr, C, Tibbs, MA and Downs, M (2002). Moving towards a special kind of care for people with dementia living in care homes, NTResearch, 7 (5): 335–347

- feel more valued and included in their community
- be listened to and understood.

1.5 Advocates and advocacy schemes work in partnership with the people they support and take forward their views and wishes. Advocacy ultimately promotes equality, social justice and social inclusion, and can empower people with dementia to speak up for themselves. It is important to recognise that advocacy involves speaking out about people's views, wishes and rights, and that advocacy does not involve making decisions in the 'best interests' of people with dementia, or making decisions on their behalf[5].

1.6 Advocacy for people living with dementia is:

- a free and individual service potentially available for every person with dementia and/or carers of people with dementia
- the provision of balanced and impartial information
- independent from statutory organisations
- help for people with dementia to voice their views, wishes and needs
- speaking for a person with dementia if they cannot speak for themselves
- supportive of self-empowerment
- always driven by a person living with dementia's defined agenda.

1.6.1 Advocacy is not:

- a substitute for a statutory provider's complaints system
- a 'befriending' service
- advice-giving
- a tool to disrupt delivery of good quality care
- a replacement for social workers, solicitors or other expert professionals
- compulsory for people to use (except where there is a legal requirement for an IMCA service)
- a mechanism to replace effective processes for service user participation.

[5] Cantley, C, and Steven, K (2004). Feeling the way: Understanding how advocates work with people with dementia, Dementia, 3: 127–143.

1.7 In addition to IMCAs, who relate directly to the provision of care and treatment by statutory providers, there are several models for the delivery of advocacy services[6]:

- **Self advocacy** – involves speaking up for oneself.
- **Peer advocacy** – involves a person who has experienced similar difficulties and discrimination advocating for another.
- **Volunteer (citizen) advocacy** – involves an independent unpaid volunteer or citizen advocate working in a one-to-one relationship with a person who needs support to achieve what they want or to exercise their rights.
- **Independent professional or paid advocacy** – involves the use of paid advocates usually supporting people to deal with specific issues or problems until that issue is resolved.

1.8 The advocacy role may include two types of advocacy, non-instructed and instructed.

Instructed advocacy
The advocate is clearly instructed by the service user and works to an agenda set out through a process of negotiation between the two parties, led by the service user. This type of advocacy depends on the person themselves being able to express their views. The advocate may use a range of skills and tools to create an environment where a person with fluctuating capacity is given every opportunity to express his or her views.

Non-instructed advocacy
Non-instructed advocacy involves taking affirmative action with or on behalf of a person who is unable to give a clear indication of their views or wishes in a specific situation. The non-instructed advocate seeks to uphold the person's rights, ensure fair and equal treatment and access to services, and make certain that decisions are taken with due consideration for their unique preferences and perspectives[7].

1.8.1 There are significant differences in the way the non-instructed advocacy process is established, led and enacted[8]. There is a requirement of advocates to use a far greater level of judgement than in instructed advocacy. The issue of judgement is a key factor in defining non-instructed advocacy. Without a clear steer from the service user, the advocate is obliged to judge the precise nature of the person's concerns, the best methods for seeking redress, and the criteria for a successful outcome. The advocate gathers information from a range of people about the

[6] Cantley, C., Steven, K., and Smith M., (2003). Hear what I say: Developing dementia advocacy services, Newcastle upon Tyne: Northumbria University.
[7] Henderson, R (Action for Advocacy) (2007). Non-instructed Advocacy in Focus, [online] Available at: http://www.aqvx59.dsl.pipex.com/What_is_non_instructed_advocacy.pdf [Accessed 15 July 2012]
[8] Wells, S (2006). Developments in dementia advocacy: Exploring the role of advocates in supporting people with dementia, London: WASSR.

history of the person with dementia and the sort of choices they made in their past. The advocate also uses every means possible to elicit the client's wishes including using reminiscence and observation where appropriate.

2 Alzheimer's Society advocacy services

2.1 The Alzheimer's Society (the Society) service model complies with the key principles of the Advocacy Charter, Quality Standards for Advocacy Schemes[9] and associated code of conduct.

2.2 The Society is independent both operationally and structurally from other organisations and has its own policies and procedures regarding:

- putting people first
- empowerment
- equal opportunity
- accessibility
- accountability
- supporting advocates
- confidentiality and complaints.

2.3 Society services comply with the Mental Capacity Act 2005 (England and Wales) and the associated code of practice, with particular regard to:

- **a presumption of capacity** – every adult has the right to make his or her own decisions and must be presumed to have capacity to do so, unless it is proved otherwise
- **individuals being supported to make their own decisions** – a person must be given all practicable help before anyone treats them as not being able to make their own decisions
- **unwise decisions** – just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision

[9] Action for Advocacy (2006). Quality standards for advocacy schemes: Based on the advocacy charter. [online] Available at: http://www.actionforadvocacy.org.uk/articleServlet?action=list&articletype=23 [Accessed 15 July 2012]

- **best interests** – an act done or decision made under the act, for or on behalf of a person who lacks capacity, must be in their best interests

- **the least restrictive option** – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

2.4 The Society provides both instructed and non-instructed advocacy services for people with dementia and carers. It is important to note that where a request is made for advocacy for a person with dementia and their carer, the carer receives a separate service where a conflict of interest may exist. The Society may also offer advocacy to groups of carers, supporting them to advocate for the person for whom they care.

2.5 Services may be provided by volunteers or by paid advocates. Where both are available, cases will be allocated by an Advocacy Manager and will be dependent on the complexity of the issue, availability of advocates, current case load, geography etc.

2.6 Working with Independent Mental Capacity Advocates (IMCAs)

2.6.1 The Mental Capacity Act 2005 made it a duty for local authorities and NHS bodies to involve/instruct IMCAs for people who:

- are facing a decision about long-term move (for example into residential/care home) or about serious medical treatment[10], and;
- lack capacity to make a specified decision at the time it needs to be made, and;
- have nobody else who is willing and able to represent them or be consulted in the process of working out their best interests, other than paid staff.

They may also be involved in other decisions concerning adult protection procedures, even in situations where there may be family and friends to consult.

2.6.2 Unlike other advocates, IMCAs have rights and duties under the Mental Capacity Act to provide statutory advocacy. They have the right to access relevant health and social care records

2.6.3 Where people with dementia have an Alzheimer's Society advocate, the person would still be entitled to an IMCA where the criteria above exist. The IMCA will provide statutory advocacy related to these best interest decisions and will consult with the Society advocate in addition to family and friends (where appropriate).

[10] An IMCA cannot be involved if the proposed treatment is for a mental disorder and that treatment is authorised under Part IV of the Mental Health Act 1983. However if the person is being treated under the Mental Health Act and the proposed treatment is for a physical illness, for example cancer, an IMCA can be involved.

3 Rights, personalisation and advocacy

3.1 The Society supports both a rights-based[11] and personalised approach to advocacy through:

- increasing the scope of advocacy activity to ensure that advocacy is available to people who fund their own care, or fall below eligibility criteria for public funding
- providing flexible support to meet possible changes to the type of support that people ask of advocacy services
- enabling people to access support beyond that offered by conventional, more traditional services. This could mean supporting people to increase their contribution to and participation in community life, enriching both the life of the individual and the community.
- having a key frontline role in ensuring that personal choice and control is achieved
- helping the person to understand what their legal and human rights are and understanding what other people's or organisations' responsibilities and duties are towards them. This is particularly important in situations where there are safeguarding concerns.

4 Advocacy and safeguarding vulnerable adults

4.1 Alzheimer's Society is committed to safeguarding all those we work with from abuse and neglect. Safeguarding is the responsibility of all Society employees and volunteers. It is the expectation of the Society that our employees and volunteers will undertake the safeguarding training required for their roles in order to be able to identify and respond appropriately to safeguarding concerns with support from their line manager. Employees and volunteers should also maintain awareness of the Society's policies and procedures relating to safeguarding, the full details of which can be found on the safeguarding pages of Arena.

4.2 Advocacy came into being as a fundamentally grassroots response to abuse, neglect and discrimination[12] and can be a crucial component in the protection of vulnerable adults from abuse. Advocacy services will often be asked to provide services in the event of concerns about abuse, or identified cases of abuse.

4.3 Advocacy services may receive direct referrals when a known safeguarding issue is already identified and under investigation or advocates may uncover concerns around safeguarding during advocacy for another issue. The aim of advocacy in

[11] Action for Elder Abuse and Action for Advocacy (2007) Elder abuse advocacy toolkit [online] Available at: http://www.elderabuse.org.uk/Documents/AEA%20guide%20-%20Advocacy%20-%20toolkit.pdf [Accessed 15 July 2012]

[12] Dunning, A (1998). 'Advocacy, empowerment and older people' in Bernard, M and Phillips, J, The Social policy of old age: Moving into the twenty-first century, London: Centre for Policy on Ageing.

safeguarding is to assist the person to be clear about the abuse they are experiencing, to provide options to overcome the abuse, and advise of possible consequences of any choices they make.

4.4 Society staff and volunteers have a duty of care in identifying and alerting statutory authorities about concerns over abuse. Staff and volunteers must follow the Society's policy on safeguarding adults.

4.5 If staff or volunteers have concerns involving another member of staff or a volunteer they must not discuss their concerns directly with anyone other than their line manager or nominated senior staff. Advocates should also refer to the Society's whistleblowing policy for further information.

5 Values and principles

5.1 Principle service aims

Advocacy services provided by the Society aim to empower and support people living with dementia to express their views, wishes and concerns. The service will support them in their choices and rights. Advocates will provide information about and support to access services across all providers. Advocates will help at a time of transition or crisis.

This service is also expected to deliver a selection of the following outcomes:

- Service users have been helped to identify the problems they face and what they want from the advocacy process.
- Service users feel that they have been able to define their own issues, problems and solutions.
- Service users feel that their confidence in dealing with an issue has increased.
- Service users feel they have a better understanding of their rights.
- Service users feel more involved and in control.
- Service users feel that the service has helped prevent crisis situations.
- Service users feel the service has improved their relationship with their family support system.
- Service users feel they have experienced improved relationships with other services.
- Service users feel empowered and able to express their views.
- Service users feel their voice is heard and there is a tangible change in systems and practices to enable them to be listened to.
- Service users' rights are protected.

5.1.1 Advocates will work to obtain outcomes the person living with dementia wants and prevent outcomes that they don't want. They will work to protect their rights and secure their entitlements.

5.2 Alzheimer's Society values

Always informed by the needs and experiences of people affected by dementia, we:

- are **inclusive**, making sure that we reach out to and involve people from every group and community
- **challenge** ourselves and others to question the status quo, be pioneering, and embrace change
- aspire to **excellence** in everything we do
- always act with **integrity** and treat everyone with respect, dignity and fairness
- **enable** others to make a meaningful contribution and realise their potential.

5.3 Alzheimer's Society operating principles

- **People with dementia will always be at the centre of everything we do** – we will work to ensure that their perspectives inform all our activities. We will enable people to maintain the maximum possible level of independence, choice and control.
- **We can't do it alone** – we seek to work collaboratively where there are clear benefits for people with dementia.
- **Being evidence based** – our actions will be based on evidence and we will prioritise our work on the basis of demonstrable need and effectiveness.
- **Involving volunteers as extensively as possible** – the continued development of volunteering is an essential means of achieving our objectives.
- **Enabling people to maximise their contribution** – we will create an environment that will enable volunteers and staff to carry out their roles effectively.
- **Acting as one Society** – operating within one strategic framework, we will respond locally to different cultural, legislative and service needs.

5.4 Service principles

- People with dementia will be our main priority. We will support people with dementia, their carers and family but the needs of family carers will not be used as a proxy for service user needs.
- We recognise that every service user is different and support an individualised and personalised approach. Service provision will be 'needs led' and not 'provider led'.

- We will listen and support people to express their concerns, problems and questions, but will respect peoples' right to privacy.

- People living with dementia will be treated with dignity and respect, and advocates will provide support to understand services and find person-centred solutions.

- We will aim to be inclusive and to reach people who may not usually use a formal service, by publicising the service via a range of sources.

- We will be sensitive to cultural and religious needs and life choices.

- We aim to tailor our service according to the expressed needs and feedback from people with dementia, their families and carers, and other stakeholders.

- We will work collaboratively with other health and care staff as well as key professionals and people who have expertise in given areas.

6 Service description

6.1 Advocacy services will facilitate building a relationship between a person living with dementia and an appointed advocate, according to the person's need. Advocates will enable service users to exercise choice and will support them in getting their views heard.

6.2 Advocacy services are free of charge to service users.

6.3 Advocacy services will work with people with dementia, their families and statutory providers to ensure a 'shared understanding' between all relevant parties of what advocacy is, how it works, and its boundaries.

6.4 Advocacy services recognise the role they play in safeguarding vulnerable adults and will work with others in the prevention of abuse of vulnerable adults.

6.5 Society advocacy services will operate independently from any other organisations including funding organisations. Advocacy services must seek to fund the service through more than one source to ensure independence from a single funding source (except where the funder is an independent funding source with no conflicts over service provision/care).

6.6 Advocacy services must be explicit in:

- who the service is for

- the geographical area covered

- the nature of issues that can be addressed

- the limitations of the service
- the processes of supporting people through the advocacy relationship.

6.7 Society advocates will not take on the role of counselling or befriending. Advocacy services will ensure that they take forward the views of the person living with dementia rather than the views, opinions and interpretations of advocates or others. This is to avoid the risk of colluding with others in achieving lesser outcomes.

6.8 In non-instructed advocacy, advocates must be sure that the views they express on behalf of a person with dementia are not 'substituted judgement'[13]. Advocates will use information about the person's whole life, for example their values and beliefs, based on former and prior decisions. Through the use of tools such as watching briefs in combination with a person-centred, human rights based approach to understand the individual's rights, the advocate will try to help formulate the person's current wish and ensure that sufficient evidence is in place to support this[14].

6.9 Advocates will operate separately from decision-making relating to best interests.

6.10 All service users accepted for referral will be allocated a named advocate who they can contact.

6.11 Advocates will explain the nature of the advocacy service at the earliest opportunity.

6.12 Service users will often experience multiple issues and the advocates must be clear on which areas they are advocating. The issues being taken forward by the advocate will be clarified and agreed with the client.

6.13 Signposting to other services such as befriending may be appropriate.

6.14 The advocate will not take forward legal issues on a service user's behalf, but may help the person with dementia to communicate their views to a legal representative.

6.15 The advocate will not provide direct financial advice but may help the person with dementia to communicate their views and wishes in relation to financial matters, in particular, where the person living with dementia is at risk of or experiencing financial abuse.

[13] Substituted judgement is a method for someone to make a choice on behalf of a person who lacks capacity based on the decision they think the person would have made if they had the capacity to do so. Such decision making authority is outside the remit of Alzheimer's Society advocates.

[14] In order to achieve this balance it is necessary for the advocate to have a baseline set of values. For Alzheimer's Society, these are based on human rights and person-centred principles and are representative of those needs which can legitimately be argued as fundamental to any person's quality of life. Advocates can then test a proposal affecting that person by examining whether it will have a positive or negative impact on any given value. This value based approach to non-instructed advocacy is usually called 'the watching brief'.

6.16 Supervision and ongoing support will be provided to paid and volunteer advocates, recognising the emotional and distressing nature of some of the issues their service users may present.

6.17 Information about the service will be available in different formats and will be appropriate for people with dementia.

6.18 The advocacy service will enable and facilitate access to local self-advocacy groups where required and appropriate.

7 Capacity and consent

7.1 It is important to be aware that just because an individual may have significant difficulty in expressing their views, it does not mean that they lack capacity. Appropriate support and adjustments should be made available, in compliance with the Mental Capacity Act 2005 (England and Wales), disability discrimination legislation and any other relevant legislation.

7.2 All service users must be assumed to have capacity to agree for an advocate to act on their behalf unless it is proved otherwise. If they do not have capacity, an advocate may continue in a non-instructed role.

7.2.1 Advocates will treat consent as on ongoing process. Advocates will record how consent is obtained from the beginning and throughout the process. The completion of a consent form is a desired but not essential element of advocacy service. Where possible a consent form should be signed but only with full understanding of what the service user is signing.

7.3 Withdrawal of consent

If a service user indicates at any time that they do not wish to continue with the service, this should be respected. This includes non-verbal clues that the person does not wish the advocate to be there. Advocates should be mindful that this may be due to other factors and should discuss this with their manager.

7.3.1 If the service user repeatedly indicates that they are reluctant to engage with the service, the service manager should consider:

- if the service user no longer wishes to have advocacy
- if the service user would want advocacy from another advocate where available
- whether the person's capacity is affecting their view.

7.3.2 All discussions and action must be recorded.

8 Service access

8.1 **Eligibility:** The Society provides both instructed and non-instructed advocacy services for people with dementia and carers. It is important to note that where a request is made for advocacy for a person with dementia **and** their carer, the carer should receive a separate service where a conflict of interest may exist.

8.2 Advocates will deliver the services in the most appropriate place for the service user. This may be in the person's home, in a Society office or another agreed location. The advocates must consider both their own safety and that of the service user in deciding upon a location. Advocates must have completed personal safety training and follow the Society's lone working policy.

8.2.1 Managers have a responsibility for ensuring the establishment of safe working practices such as a guardian system for monitoring staff and volunteers' whereabouts and safety.

8.3 Where required, the advocacy service will ensure that local minority communities and those unable to self-refer can access the service and will have systems for accessing community language/sign language interpreters and/or advocates.

8.4 Alzheimer's Society holds public liability insurance and all premises must comply with the Society policy on health and safety.

8.5 Referrals to the service may be from a range of sources including health or social care professionals.

8.6 Every service will have a recognised referral pathway, either through the advocacy manager or other appropriate system. Decisions will be made on whether the referral meets the eligibility criteria.

8.7 Referrals will be responded to within five working days. People will not be placed on a waiting list without an initial meeting (except in exceptional circumstances).

8.8 The advocate will work with the service user on the issues presented at the referral. Any further issues identified after this time will be reviewed and prioritised with the service user.

8.9 Preferred outcomes will be discussed with the service user and a course of action mutually agreed. This agreement will include time lines, boundaries and when the service will be reviewed with a view to closing. The agreement may include:

- agreement on gathering and presenting up-to-date and accurate information to help service users make informed choices but not giving advice
- talking to, and corresponding with, family members or other professionals with the service user's permission but not making decisions or choices on behalf of service users

- representing the person's expressed views and wishes but not taking action independently of the service user

- agreement that all correspondence will be shown to the service user.

8.9.1 The agreement between the service user and advocate must be reviewed regularly with the service manager.

9 Working with families and carers

9.1 Advocacy services will respect the views and feelings of carers and family members and must provide relatives with clear information about the advocacy service to prevent misconceptions and reinforce that advocacy is for the person with dementia rather than the carer.

9.2 Advocates must be clear that the issues presented are those of the person with dementia and not the carer. Where possible and appropriate the service will support relatives to advocate for the person with dementia and where necessary refer relatives to other agencies for support or advocacy in their own right.

10 Case management

10.1 The service will operate a case management system. The system must be set up to take into account the skills and experience of advocates so that they are allocated to the most relevant cases.

- Cases involving individual service users will be classified as open or closed.

- All cases should be viewed as an episode that has a beginning (referral), a period of advocacy provision and an end (usually when the issue is resolved).

- Cases involving individual service users may be opened and closed a number of times and the review period will support this approach. Service users' files can be endorsed with 'suspended'. This gives advocates and advocacy managers access to their history if and when the file is reopened on re-referral.

10.2 In terms of case management, a case should be regarded as 'active' where:

- advocates have had an interaction with the service user in the last three months

- the advocate still has an appointed visit to make

- the advocate still has an outstanding action from an appointed visit.

10.3 Closure

Advocacy services will have clear criteria about ending the contract/agreement and exit strategies should be planned, discussed and agreed.

10.3.1 Advocacy managers must provide supervision and support to advocates at the point of withdrawal if required.

10.3.2 Caseloads must be kept under ongoing review by individual advocates and line managers.

11 Recording and confidentiality

11.1 It is important that only issues discussed with the client or on which the advocate has good evidence about the client's wishes are recorded. Records should include information on how the advocate ascertained the client's wishes and written notes on the interaction between the advocate and the person with dementia. Records must record the range of approaches and communication. Advocates and managers must comply with the Society's policies on data protection, privacy and confidentiality.

11.2 Written records must show how consent was obtained and how ongoing consent is established, for example if there is continued observed engagement with the advocate, a brief description of this should be recorded.

11.3 The advocate must always explain to the person with dementia what is being recorded and how this will be used. Staff and volunteers must comply with the Society's record management policy and procedures.

11.4 Advocates and managers must follow the Society's protocol on data sharing and must obtain the person's consent before sharing information with others including family members, professionals and other service providers (see 12.5). Requests for access to records must be made in writing by using the Society's data subject access form and submitted to the head of Risk and Compliance.

11.5 Information may only be shared where:

- it is necessary to safeguard or promote the physical or mental well-being of the service user
- it is necessary to protect the individual from harm
- it is necessary to prevent or detect a crime.

11.6 Storage and archiving of records must comply with the Society's record management policy for services and the retention and disposal of records schedule.

12 Advocacy staff and volunteers

12.1 Advocates will:

- have an understanding of the principles of advocacy and the rights of people with dementia and their carers
- have an understanding of inclusion and the need to treat people from all backgrounds with dignity
- raise awareness of the advocacy service, including raising awareness of the needs of people with dementia and their carers
- take on advocacy cases as allocated by the advocacy manager
- establish a relationship with a person with dementia and/or their carer
- assist people with understanding and securing their rights to the care and services they need
- ensure ongoing consent from the service user at all times
- provide accurate and comprehensive information to enable people to make informed choices
- support self-advocacy, or represent the views of the advocacy client in relation to their health and social care provision
- undertake further development as discussed and agreed with the line manager
- keep the advocacy manager fully informed at all times of the progress of cases and to attend supervision meetings with the advocacy development manager
- keep clear and precise records for all service users and be aware of confidentiality policy and safeguarding vulnerable adults alerting procedures
- contribute to the evaluation of advocacy services
- have enhanced CRB and professional indemnity insurance
- comply with all appropriate Society policies and code of conduct.

12.2 Advocacy managers will:

- have an understanding of the principles of advocacy and the rights of people with dementia and their carers

- have an understanding of inclusion and the need to treat people from all backgrounds with dignity

- promote advocacy services, including raising awareness of the needs of people with dementia and their carers

- ensure that all avenues are explored to achieve a positive outcome for the individual

- be responsible for the recruitment, induction supervision, appraisal, development and performance management of staff and volunteers working within the service

- ensure staff are adequately trained, supported and supervised in accordance with relevant policies and quality standards

- work within the principles for the provision of advocacy in accordance with the Society's standards and comply with the national advocacy charters, as appropriate

- offer information (and where appropriate, representation) in order to empower people living with dementia or their carers to make informed decisions regarding care and treatment

- maintain up-to-date information in an accessible format and be aware of welfare rights, benefits, relevant legislation and availability and eligibility for local services

- raise awareness of the advocacy service and build good relationships with local safeguarding authorities

- develop networks with partner organisations who also work in the field of dementia – mental health, disabilities, benefits and income advice including primary and secondary care, social care and health, and welfare benefit agencies – with the aim of signposting clients to appropriate services

- identify and analyse trends and issues within the advocacy service, producing information and written reports as required

- seek and evaluate client feedback to understand whether needs are being met, and plan any necessary adjustments

- have enhanced CRB and professional indemnity insurance.

12.3 Advocacy volunteers will:

- have an understanding of the principles of advocacy and the rights of people with dementia and their carers

- have an understanding of inclusion and the need to treat people from all backgrounds with dignity
- take on advocacy cases as allocated by the advocacy manager.
- establish a relationship with a person with dementia and/or their carer
- provide accurate and comprehensive information to enable people to make informed choices
- support self-advocacy, or represent the views of the advocacy client in relation to their health and social care provision
- maintain accurate and legible records
- attend learning and development and regular supervision activities in support of the role
- keep appropriate colleagues fully informed at all times of the progress of cases and attend support and supervision meetings on a regular basis
- contribute to any monitoring or evaluation processes as required
- respect service standards, appropriate boundaries and recognise the range of policies and procedures that impact on the activity being carried out
- have enhanced CRB and professional indemnity insurance.

13 The brand

13.1 The advocacy service is an existing service provided by Alzheimer's Society. In accordance with Alzheimer's Society's brand values, the advocacy services provided will be accessible, of a high quality, underpinned by voluntary support and place people with dementia at the heart of all activity.

14 The people

14.1 Staff structure

Advocates are usually managed within a locality management structure but there may be regional variations. To ensure equity of approach and shared learning, a strong network of area and/or locality support workers and volunteers is encouraged.

14.2 Recruitment and selection

A rigorous recruitment and selection process, in line with Society policies, followed by a thorough induction programme and post-induction assessment, ensures that staff and volunteers provide quality services throughout the Society.

14.3 Staff and volunteer development

The service described above requires staff and volunteers to be highly skilled and supported in order to maximise the outcome for the people using the service.

14.4 Staff, volunteer advocates and service managers will receive:

- a structured and thorough induction
- structured and regular supervision
- ongoing training
- peer support.

15 Training and support

15.1 All staff and volunteers will have access to training on:

- the principle and process of advocacy
- general communication skills
- communication with people with dementia
- legal issues
- human rights
- ethical issues
- disability equality/race equality training
- code of conduct and professional boundaries
- health and safety
- lone working.

15.2 Where possible, staff and volunteers should be supported to undertake additional national advocacy qualifications.

16 Service evaluation and monitoring

16.1 All Society services are evaluated to inform continuous improvement. The Society seeks to ensure that we provide high quality services and that as a charity we are using our charitable funds in the most appropriate manner. Accordingly, we consider the following attributes to be the key indicators for quality and we aim to ensure that services are designed, developed and continually assessed against the following:

- availability and access (inclusiveness, equity)
- safety and effectiveness (fit for purpose)
- service user involvement in the development and continuous improvement of services
- choice, through the availability of a range of services
- collaborative and partnership working
- sustainability
- value for money (where appropriate).

16.2 The service will be both formally and informally evaluated in terms of perceived benefit to people with dementia and/or carers. Sources of information will include case notes, advocacy agreements and registers as well as self-completion surveys and observation or interview by another advocate. The advocacy scheme's funding bodies will be provided with relevant written monitoring information and a summary of work will be publicised by the advocacy scheme, for example in the form of an annual review of activities.

16.3 The Society will monitor the following outputs from the advocacy services:

- number and sources of referrals accepted, broken down by age, gender and ethnicity of service user
- number and sources of referrals refused with reasons, broken down by age, gender and ethnicity of service user
- number of active cases at the end of the quarter, broken down by case type and age, gender and ethnicity of service users
- number of cases closed, broken down by case type, showing average number of hours spent, with summary of outcomes
- emerging patterns of referrals (eg by type of intervention or source of referral)

- record of time spent on individual cases
- records of any complaints or compliments the service receives
- recordable activities per service user, eg sorting out a care package
- staff turnover and records of training and supervision for staff (aggregated)
- relevant financial data on cost and expenditure
- overall service capacity (actual vs. capacity) as a percentage.

16.4 The advocacy service is also expected to deliver a selection of the following outcomes:

- Service users have been helped to identify the problem they face and what they want from the advocacy process.
- Service users feel that they have been able to define their own issues, problems and solutions.
- Service users feel that their confidence in dealing with an issue has increased.
- Service users feel they have a better understanding of their rights.
- Service users feel more involved and in control.
- Service users feel that the service has helped prevent crisis situations.
- Service users feel the service has improved their relationship with their family support system.
- Service users feel they have experienced improved relationships with other services.
- Service users feel empowered and able to express their views.
- Service users feel their voice is heard and there is a tangible change in systems and practices to enable them to be listened to.
- Service user's rights are protected.

16.5 Data from across the organisation's advocacy services will be amalgamated and compared to give a wider view of the services in terms of quality and best practice, which will be shared.

17 Alzheimer's Society service standards and complaints process

17.1 The advocacy service will adhere to Alzheimer's Society customer service for information services general standards.

17.2 We will provide clear guidelines on accessing our complaints procedure.

17.3 We will provide a prompt response to all enquiries to the service. To achieve this we will:

- respond to all written general enquiries within five working days
- respond to complex written enquiries within ten working days
- return telephone messages and email enquiries within two working days.

All service specifications are subject to annual review. If you have any comments on the specifications please contact the Process and Quality team. Comments, suggestions and feedback will be considered at the next review date.