



**Alzheimer's  
Australia**  
Living with dementia

## **Policy and Practice Guidelines: *Privacy and Access to Personal Information***

### **Scope**

This document sits under the National Philosophy, Principles and Service Standards of Alzheimer's Australia.

**Principles and Policy** - apply to all activities undertaken by Alzheimer's Australia and its member Associations involving service users, employees, volunteers, contractors and consultants. They were adopted by the Board on 22 March 2003.

**Practice Guidelines and Appendices** – are available for State/Territory Associations to adapt for their own use as required.

### **References**

- Alzheimer's Australia (Vic) Privacy Policy and Procedures (issue date 2002)
- Alzheimer's Australia (Vic) Informed Consent Policy and Procedures (issue date 2002)
- Commonwealth of Australia Privacy Act 1988, Reprinted on 21 December 2001
- Information Privacy Act 2000
- Health Records Act 2001
- Draft Proposal to the Health Records Bill
- Freedom of Information Act 1982
- Public Records Act 1973

### **Principles**

- All service users, employees and volunteers of Alzheimer's Australia and its member Associations have the right to privacy of personal information.
- Personal details and sensitive material in any form shall be managed with diligence, and, where relevant, privacy issues will be explained in detail.
- Associations shall be open and accountable about how personal information is handled.
- People shall have the opportunity to make an informed choice about whether their personal details are recorded and how this information is used.
- A person's consent shall be sought when an Association proposes to use personal information for a purpose other than the primary purpose.

# **Policy**

## **1. Collection of information.**

- Consent from the individual shall be obtained;
- Information about the Association will be provided;
- Details of who may have access to the information will be provided;
- Only information necessary for the activities of the Association will be collected and recorded; and
- Information given in confidence will remain confidential.

## **2. Use and disclosure of information**

- In general, Associations will use or disclose information only for the primary purpose for which the information was collected;
- When information is to be used or disclosed for other than the primary purpose for which it was collected consent will be obtained wherever practicable, and the information will be de-identified wherever possible; and
- Secondary use or disclosure may occur only where there is a strong public interest in doing so (e.g. where there is a serious threat to life, where disclosure is required by law or for research which is in the public interest and complies with guidelines).

## **3. Data Quality**

- Associations will take reasonable steps to ensure that the information they collect, use, retain or disclose is accurate, complete, up to date and relevant to their functions or activities.

## **4. Data security and data retention**

- Associations will take all reasonable steps to protect the information they hold from misuse and loss and from unauthorised access, modification or disclosure;
- Information will not be deleted unless authorised or required by law;
- Information will be held for at least seven years subject to any specific legislation to the contrary.

## **5. Openness**

- Associations will document clearly the policies and procedures on the management of information and will make this information available to the public on request; and
- On request, Associations will make known to an individual whether information is held on them, and steps to be taken to obtain access to that information.

## **6. Access and correction**

- Associations shall provide individuals with access to the information they hold.
- Associations shall take reasonable steps to ensure the information they collect is accurate, complete and up to date.

## **7. Identifiers**

- Associations shall only use identifiers where it is necessary to carry out its functions.

## **8. Anonymity**

- Individuals shall have the option of remaining anonymous.

## **9. Transborder data flow**

- Information will only be transferred outside Australia with the consent of the individual or where legal obligations apply.

## **10. Transfer or closure of an Association.**

- In the event of an Association being sold, transferred, closed down or amalgamated, it will take all reasonable steps to inform every individual who has received a service of arrangements for dealing with their health information.

## **11. Transfer to another health provider.**

- In the event that a service user of an Association wishes to transfer to another health care provider, the Association will upon request, provide the new provider with a copy or written summary of the Individual's health care information.

# **Practice Guidelines**

## **Collection of information**

- Before collecting personal information, or as soon as practicable thereafter, Association staff and volunteers will seek the consent of the individual. (Refer Appendix A 'Guidelines for gaining consent to record personal information')
- Information may be collected in the absence of consent if:
  - The person is incapable of giving consent and their representative is not contactable. OR
  - The individual or another person is at serious or imminent risk. OR
  - A member of the treating team is collecting the information from another member of the treating team.
- General brochures explaining the Association's services will be made available to service users at the commencement of the service.
- Statement of User Rights (see Appendix B 'Statement of user rights') will be displayed in public areas, and copies will be provided to new service users of the Association.
- Information will only be collected on a need to know basis, ie. we will not seek more information about a service users' personal life, financial situation or living circumstances than is needed to undertake the task required.
- We will collect information about an individual directly from that individual where it is reasonable and practical to do so.
- We will take reasonable steps to ensure that where information is collected from a third party, the subject of the information is made aware of this.
- We will make individuals aware that where personal details are provided they will be recorded, for what purpose the information is collected, whom it will be shared with and under what conditions. We will seek verbal consent from service users for sending out of future information and record their response (see Appendix C 'Guidelines for gaining consent to use personal information within the Association for secondary purposes')
- Client notes will be written taking the following factors into consideration: objectivity, respect for the feelings and dignity of the person with dementia, their families and carers, the right of service users to request access to their own files, freedom of information, and court regulations governing subpoena of files.
- At the commencement of all training courses provided by the education staff, the educator will:
  - Ask the participants to treat any information disclosed by other participants as confidential
  - Inform the participants that their contact details will be added to our data base, and that they may receive information from us regarding further training opportunities, but that they can request to have their details removed at any time

- If the Association is an RTO, inform the individual of the requirement to record the following information:
  - Student enrolments
  - Attendance
  - Completion
  - Assessment outcomes (where applicable)
  - Recognition of Prior Learning granted (where applicable)
  - Results
  - Qualifications issued
  - Grievances

## **Use and Disclosure of Information**

- Information collected by Association staff and volunteers will only be used for the purpose for which it was collected.

### ***Use of information within the Association for a secondary purpose***

- If the Association wishes to use the information for a purpose other than the primary purpose we will obtain the individual's consent to do so.
  - People in contact with the Association will be given the opportunity to make an informed choice about participating in a mailing list, including fundraising requests and promotional materials.
  - Where appropriate new service users may be offered the opportunity to become members of the Association. If the person chooses to become a member, this will eliminate the need to seek further consent in relation to receipt of mailed information. Individuals are made aware of this at the time of becoming a member.
  - Individuals who are not members, must give their consent to be included on a mailing list.
  - Where considered appropriate, consent is sought at the end of a contact. (see Appendix C 'Guidelines for gaining consent to use personal information within the Association for secondary purposes')
  - When a person gives consent to be included on a mailing list, this will be recorded on person's file and person's name and mailing address forwarded to fundraising staff.
  - When a person declines inclusion in a mailing list, this is recorded on the file.
  - If a person changes their status at any stage, the file will be adjusted and fundraising staff notified.
- If the Association wishes to use the information for research or evaluation of the service, it need not obtain consent, but will take reasonable steps to de-identify the information.

### ***The release of information to another person or agency***

- Verbal or written consent should be obtained from the individual prior to releasing information to another person or agency
- Only information that is directly relevant to the immediate needs of the individual will be released to another person or agency.
- The person will be provided with a full explanation of:
  - To whom we are proposing to release personal information
  - The purpose for releasing that information
  - Specifically what information will be released
- The person will be given ample opportunity to consider the request and make a decision.
- If the person consents to the release of the information, they will be asked to complete the 'Release of Information Form' (see Appendix D). If consent obtained by telephone, staff shall complete section A and C of the form only.
- Once the form has been completed the release of information can proceed.
- If paper files kept, the form shall be stored in the person's file.
- If electronic files kept, details from the form to be entered.
- If disclosing the information is necessary for law enforcement functions, Association staff and volunteers will refer the matter to their manager prior to making the disclosure.
- If the disclosure is considered necessary to prevent or lessen a threat to a person's life or well being, Association staff and volunteers will refer the matter to their manager prior to making the disclosure.
- When a direct family member requests the information, the matter should first be discussed with the manager. The disclosure may occur on compassionate grounds or when it is necessary to provide the health service. In this instance the following must apply:
  - The individual must be incapable of giving consent and there is no legal guardian.
  - The disclosure must not be contrary to any expressed wish of the individual.
  - The information that is disclosed should be limited to that which is necessary.
  - Where education staff are delivering an accredited course, the educator will inform the participants what information the Association is required to provide to the relevant State/Territory education body.

## **Openness, Access to and Correction of Personal Information**

### ***Correction of personal information:***

- If the Association holds personal information about an individual and the individual is able to establish that the information is not accurate, complete and up to date, the Association will take reasonable steps to correct the information so that it is accurate, complete and up to date. The individual may request access to their information to ensure that it is accurate, complete and up to date.
- If the individual establishes that information about them is incorrect or incomplete, the Association will correct the information by noting that correction, the name of person making the correction and the date. We will notify the individual within 30 days of our decision to correct the information. We will furthermore make every effort to contact other agencies that may have received the information, of the correction.
- If the Association finds it impractical to correct information (eg the form in which the information is held makes correction impossible) we will ensure that only the correct information is available to the treating team, and access to the incorrect information is restricted.
- If for any reason the Association is unwilling to correct the individual's information, we will provide reasons for that decision in writing, and will ensure that the individuals request to make the correction is recorded/filed with the information in question.

### ***Openness: -***

- The Association will take reasonable steps to inform service users, generally, what sort of personal information it holds, for what purposes, and how it collects, holds, uses and discloses that information.
- General brochures explaining user rights (see Appendix B), including the right to access their own information and the process for doing so will be made available to all service users at the commencement of the service.

### ***Request for access by the individual: -***

- A request for personal access to a client file should be made in writing stating the individuals name and address, specifically which information they are requesting access to, and the way in which they would like to access the information.
- There are three ways to have access;
  1. Viewing/reading the information or a printout of it.
  2. Receiving a copy of the information or if the individual agrees, an accurate summary of the information.
  3. Viewing the information and having it explained through a consultation process.
- If the request is made orally, the Association may seek a written request.
- The Association may also request proof of identity.
- The Association will respond within 45 days of receiving the request either by providing the information requested, or providing reasons for denying access.

- Where a client requests access to their own records, only information provided by that client will be released. For eg. In situations where there is more than one client of the same family, details provided from each client will be treated and recording separately.
- Access may be denied under particular conditions. In this instance, the individual may request that the information be sent to another practitioner who will view the information and consider the legitimacy of denying access. In this way the individual can be assured that the information is not being withheld in breach of the Privacy Act.
- Wherever direct access by the individual is impracticable or inappropriate, the Association and the individual should consider whether the use of mutually agreed intermediaries would allow sufficient access to meet the needs of both parties.
- The Association will provide reasons for denial of access or correction. If the individual does believe that the Association is acting contrary to the Act by denying access to their personal records, they may seek conciliation through the relevant State/Territory body.

***Request for access by a third party: -***

- Where access is requested by a person of another individual's information, these requests will be discussed with the Manager prior to providing access.
- Access to a third party is acceptable if the individual has given the Association written authority to provide access to the person named in the authority.
- Where information about an individual is given by a person other than the individual, in the strict confidence that it will not be passed on to the individual (Eg in the case of a carer disclosing details about the person with dementia), that information is subject to confidentiality and will not be communicated to the individual with whom it relates.

## **Retention Storage and Security of Information**

### ***Security***

- All personal information will be kept in files, either paper or electronic files.
- Files will not be deliberately damaged, deleted or altered in any way. Where errors are made, they will be corrected. For paper files, a single line will be drawn through the incorrect entry and liquid paper will not be used.
- Access to computer systems will be protected by passwords
- Files should not be removed from offices. However, where transfer from one office to another is necessary, files will be transported securely.
- Paper files will be stored in locked cabinets unless in use.
- If personal information is transferred by fax, the fax will be accompanied by a cover page noting that the information is confidential.
- Personal information will not be transmitted by email.

### ***Storage and Retention***

- Paper files will be retained for a period of seven years from the time of last contact with the individual, as is required by law.

- Electronic files/database will be maintained indefinitely
- Financial information including donations will be kept for seven years in accordance with tax law.
- Ephemeral or facilitative material (eg data input forms, membership forms etc) will be retained for a period of two years from the time of last contact with the individual.
- All personal information that is no longer required will be shredded.

## **Identifiers**

- Identifiers will not be used in the normal course of business
- If the use of identifiers is necessary for a specific purpose, they will be unique. We will not use identifiers assigned by a public sector agency.
- Identifiers assigned by public sector agencies will remain confidential.

## **Anonymity**

- When seeking consent to collect information, clients will be advised of their right to anonymity. In this instance no identifying information will be collected or recorded.

## **Transborder Data Flow**

- Requests made other than by the individual, to transfer health information outside Australia will be referred to the Manager.

## **Transfer or closure of the Association**

- In the event of the Association being sold, transferred, closed down or amalgamated, we will place a public notice about the closure or alike in local newspapers.
- The Association will make every attempt to contact existing service users in writing to notify them of the closure or alike, and of the process for dealing with their information.
- Health information held by the Association will be transferred to the new owners/provider within 21 days of giving public notice.

## **Transfer of information to another provider.**

- When an individual decides to transfer to another health care provider the Association will, on request: -
  1. Provide a copy of the individual's information to the health care provider in a timely manner. OR
  2. Provide an accurate and comprehensive summary of the information in a timely manner.
- The information will be transferred by certified mail, or handed directly to the individual concerned.

# Appendix A

## Guidelines for Gaining Consent to Record Personal Information

In order to meet our responsibilities regarding privacy legislation and user rights, staff and volunteers must advise individuals of our intention to collect and record information about them.

This should be done at some point during the first contact. If this is not possible, as soon as is practicable thereafter.<sup>1</sup>

Step 1            During the conversation ask the person if they have had contact with the Association before?  
Has anyone spoken with them about how we collect and handle information they provide to us?

Step 2            If the answer to these questions is no, the following information must be provided to the individual.

- The fact that we are recording their information.
- The purpose for collecting it.
- With whom we share that information.
- Their right to remain anonymous if they wish.

It can be difficult to find the right time and the right words to use to do this, particularly if a person is distressed and anxious to tell their story. How and when during that first contact you do this is up to you. Every worker has their own style and it is important to use your discretion about how best to cover these points, while still engaging the client.

To assist you, here is an example. At some point during the first contact you might say: -

***“It is important that I tell you that I am/will be writing down the information you give me so that we can provide the best possible service. Your information will be treated confidentially, and will not be shared with anyone outside the (relevant service/team) without your consent. You may also choose to remain anonymous if you prefer. Are you happy for me to do this?”***

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<sup>1</sup> There is some debate about whether it is preferable to gain consent at the beginning of the contact, towards the end, or with follow up written material. States/territories may need to consider their preference. The National Privacy Principles (Privacy Act 1988, reprinted Dec 2001) state that “At or before the time (or, if that is not practicable, as soon as practicable after) an organisation collects personal information about an individual from the individual, the organisation must take reasonable steps to ensure that the individual is aware of...” (their privacy rights).

If, toward the end of the conversation, some contact information remains incomplete, it may be necessary to ask the person for that information. Eg: -

***“Could I ask you some final questions to ensure that I have all the relevant information?”***

It is difficult to cover all the detail about user rights during a first call. Therefore, it is also important that we provide written information.

Step 3            A brochure about the Association and a brochure/information sheet of User Rights including privacy principles (see Appendix B) should be mailed/provided to all service users.

Step 4            Existing service users.

Workers shall provide all current service users with a copy of both brochures.

## Appendix B

### Statement of User Rights (for brochure/information sheet)

What you can expect when you use the services of Alzheimer's Australia (*State/Territory*)

Alzheimer's Australia (*State/Territory*) provides a range of services to support people living with dementia, their families and carers.

#### **Our Service Commitments**

When you use the services provided by Alzheimer's Australia (*State/Territory*) you can expect to:

- Be treated with courtesy and respect;
- Have your personal beliefs and privacy respected;
- Be informed of the range of services provided by the Association;
- Be informed of services provided by other organisations that may be of assistance;
- Select the services you wish to use;
- Be informed of your rights and responsibilities;
- Have a person of your choice accompany you or act on your behalf;
- Have access to interpreter services;
- Have access to your records and be informed as to how information may be used; and
- Comment on services provided.

#### **Your Privacy**

It is necessary for us to collect and record some of your personal information so that we can provide the best possible service.

- Any information you provide will be treated confidentially.
- In general, we will not disclose your personal information to anyone without your consent.
- If you are receiving counselling or support services there are times when your personal information may be shared with other counsellors or support workers so that we can provide you with the best information and support available.
- There are also occasions, though uncommon, when the law requires us to disclose confidential information. This might occur when the health or wellbeing of a person is threatened and thus there is a strong public interest in disclosing that information. Your counsellor or support worker will answer any questions you have about this.
- You may also choose to remain anonymous if you prefer.

## **Your Feedback**

Alzheimer's Australia (*State/Territory*) welcomes your feedback because it helps to improve the way services are delivered. You can do this by contacting your State/Territory Association, either verbally or in writing, to discuss your suggestions with staff. At times, the Association may also contact you directly to seek your suggestions for improving the quality of services.

If you wish to raise a matter of concern you can write or talk to:

- The staff member/volunteer providing the service;
- The Manager of the staff member/volunteer providing the service; or
- The Executive Director.

The Association welcomes comments and complaints as valuable feedback, will investigate all fairly, and will aim to learn lessons from them.

Alternatively, you may choose to contact the (*relevant State/Territory health body*) to assist you in addressing your concern.

*(provide address and phone number of relevant body)*

## Appendix C

### Guidelines for Gaining Consent to Use Personal Information within the Association for Secondary Purposes

The Association may wish to offer all service users the opportunity of becoming members of the Association, or to participate in a mailing list. Becoming a member would eliminate the need to seek further consent in relation to the receipt of mailed information (clients are made aware of this at time of becoming a member). In many cases, the most appropriate time to ask this will be at the end of a contact. I.e. at the end of a Help-line call, the end of a series of counselling sessions, the completion of living with memory loss program, or at the end of an education session.

*Suggested points to cover:*

- An invitation to become a member may include:
  - An explanation of the advantages.
  - The cost if applicable.
  - A disclosure about receiving fundraising material, and request to participate in research from time to time.
  - An assurance that the service they receive will not be affected by their decision.
  - Assure the client that their personal information will only be used for the purpose stated and will not be disclosed to any other person or organisation.
  
- An invitation to participate in a mailing list may include:
  - An explanation of the advantages. i.e. receiving information about dementia and the caring role.
  - A disclosure about receiving fundraising material and requests to participate in research from time to time.
  - Assure the client that their personal information will only be used for the purpose stated and will not be disclosed to any other person or organisation.

To assist you, here is an example. You might conclude a contact as follows: -

***“Would you like me to tell you about becoming a member of the Association”?***

*If No: - continue to the next question*

*If yes: -*

***“By becoming a member you will receive quarterly newsletters, discounts on workshops and seminars, free use of our library, information on the most recent research, voting rights at AGM, and from time to time fundraising literature, and requests to participate in research. It costs (inform of that applicable to State/Territory). Your information is treated confidentially. Becoming a member is optional and your decision will not affect the service you receive from the Association in any way. Would you like me to send you a membership form”?***

If no – continue to next question.

If yes – provide Membership registration form / Association brochure

***“Would you still like to receive information from the Association from time to time that may assist you in your caring role/experience of dementia, and at times may include research information and fundraising material? This is optional and your decision will not effect the services you receive from the Association in any way”***

If yes - Confirm and record the person’s name and mailing address. Give the clients details to fundraising staff.

If no - Thank the client and conclude the contact as you would normally.

# Appendix D

## Release of Information Form

### SECTION A – Client details

Clients first name \_\_\_\_\_

Relationship to person with dementia \_\_\_\_\_

Address \_\_\_\_\_

Telephone \_\_\_\_\_ (Home) \_\_\_\_\_  
(Bus/mobile)

Purpose for the release of information \_\_\_\_\_  
\_\_\_\_\_

To whom Person/Agency/s \_\_\_\_\_

### SECTION B - Written Consent form

I give my consent for the Alzheimer's Association to release my personal information/details to \_\_\_\_\_ (Name of agency or person).

Clients Signature \_\_\_\_\_ Date \_\_\_\_\_  
\_\_\_\_\_

Workers name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

#### If the client is unable to consent: -

Clients name \_\_\_\_\_

Guardians name \_\_\_\_\_

Relationship to person with dementia \_\_\_\_\_

On behalf of the above named person, I give my consent for the Alzheimer's Association to release my personal information/details to \_\_\_\_\_ (name of agency or person).

Signature of guardian \_\_\_\_\_ Date \_\_\_\_\_

Workers name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

### SECTION C - Verbal Consent form

Verbal consent obtained by: -

Workers Name \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_