



*Making dementia a priority:
changing perceptions, practice and policy.*

Alzheimer Europe privacy policy

21 June 2023

1. Introduction

Alzheimer Europe is a non-profit non-governmental organisation (NGO) aiming to provide a voice to people with dementia and their carers, make dementia a European priority, promote a rights-based approach to dementia, support dementia research and strengthen the European dementia movement.

Alzheimer Europe is registered in Luxembourg as a charity (association sans but lucratif/A.s.b.l) by the Registre du Commerce et des Sociétés, under the registration number F 2773.

Alzheimer Europe respects your privacy and handles your personal data with care. Personal data are processed in accordance with the Regulation (EU) 2016/679, the General Data Protection Regulation (GDPR). Alzheimer Europe is the **Data Controller** for all personal data collected from you.

This policy explains what personal data we collect from you, why we collect your data and how we process your data. Also, we explain the conditions under which we may disclose such data to others and how we keep that information secure.

The Alzheimer Europe website contains links to other websites. Our privacy policy applies only to our website, so if you click on a link to another website, you should read their privacy policy.

2. Changes to our privacy policy

Alzheimer Europe reserves the right to update this privacy policy at any time. Any material changes will be posted on our website. We encourage you to review this privacy policy often to stay informed of changes or updates that may affect you, as your continued use of the website signifies your continuing consent to be bound by this privacy policy.

This privacy policy was last updated on 21 June 2023.

3. What data do we collect?

Alzheimer Europe may collect, use, store and transfer different types of personal data and special category personal data depending on how and why you are interacting with us, which we have grouped together as follows:

1. **Identity** - first name, family name, gender, date of birth, ID/passport details
2. **Contact** - email address, home address, phone number, social media accounts/names
3. **Family** – family member identity data, home address, email addresses, phone number
4. **Financial** - bank details
5. **Profile** - username, profile image
6. **Additional data** - any other information you may choose to share with us that you think is relevant.
7. .
8. We may also collect, use and share **Aggregated Data** such as statistical data for any purpose. Aggregated Data may be derived from your personal data, but is not considered personal data in law, as this data does not reveal your identity (directly or indirectly). However, if we combine or connect Aggregated Data with your personal data (so that it can directly or indirectly identify you), we treat the combined data as personal data which can only be used in accordance with this Privacy Policy.

In a limited set of circumstances, we may ask you to provide [special categories of personal data](#), such as medical or health information, information on your dietary needs, or ethnic origin. Specifically, you may be asked to provide **health information** or **dietary information** when registering for our events or annual conference; and you may be asked to provide **health information or information about your ethnic origin** when you sign up for the [Alzheimer Europe Public Involvement Pool](#). The Alzheimer Europe Public Involvement (PI) Pool is a platform that allows members of the public (excluding health and social care professionals as well as service providers) to be invited to share their views on various topics and aspects of ongoing European research initiatives.

4. How do we collect your data?

(a) By **visiting and using our website**, you may provide certain information **yourself**:

- forms filled out by you,
- information contained within the content of correspondence with us,
- registration for our Annual Conference,
- information from social media
- voluntarily complete a customer survey or provide feedback on any of our message boards or via email/ tweets etc

We may also **automatically** collect certain information if you visit our website:

- technical information, including IP address, geographical location of IP, login information, browser type & version
- information about your visit (pages visited, amount of time spent in each page, visit sequence)
- cookies

Finally, information collected on our site may be stored and processed into anonymous statistics or log files for internal use, such as traffic and profile analysis.

(b) By **attending our events** we may collect and process the following data about you:

- forms filled out by you
- content of correspondence with us
- subscriptions or registration
- information from social media when you link to our website

(c) In limited circumstances, **we may collect data that is publicly available**, if there would be a reasonable expectation that an organisation such as Alzheimer Europe would process it, for example, if you are a journalist, medical expert, researcher, politician, business leader or person of note in the dementia field.

5. What is the legal basis for collecting data?

If you are an individual in the European Economic Area, we collect and process information about you only where we have legal bases for doing so under the GDPR (Art.6[1]). The legal bases depend on the products and services you use, and how you use them. This means we collect and use your information only where:

- We need the information to provide you with products and services, to produce the products or operate the services, or to provide customer service linked to provision of products or services (*“processing is necessary for performance of a **contract** between the two parties”*)
- It satisfies a legitimate interest, not overridden by your data protection rights (see point 9. below), such as for research and development, to communicate and promote our products and services, and to protect our legal rights and interests (*“processing is necessary for the purpose of **legitimate interests** pursued by Alzheimer Europe, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject”*)
- You provide your consent for us to use your information for a specific purpose (*“the data subject has given **consent** to the processing of his or her personal data for one or more specific purposes”*)

We will only process **special categories of personal data**, such as personal data revealing racial or ethnic origin, political opinions, or data concerning health, if you have provided explicit **consent** for the processing of these personal data for one or more specified purposes (Art.9[1][a] GDPR) (e.g, registration for the [PI Pool](#)).

6. How will we use your data?

Alzheimer Europe will only use your personal data, in compliance with the General Data Protection Regulation (2016/679, “GDPR), for purposes including the following:

- To provide you with products and services, such as newsletters
- To process all necessary payments
- For internal administration and record keeping
- To register for events, in particular our [Annual Conference](#)
- To register for our [Public Involvement Pool](#)
- To respond to enquiries
- To administer our digital platforms
- To manage legal and regulatory obligations
- To verify identity
- To give you the opportunity to provide us with feedback through reviews, questionnaires and surveys
- To process job applications
- To perform a contract, such as providing products and services to you
- For legitimate business purposes
- In other cases, if necessary, with your **consent**

7. Who do we share your personal data with?

We may be legally obliged to share personal data with state entities, such as tax authorities or law enforcement or regulatory bodies, for employment or financial compliance. We may also on certain occasions pass your personal data to third party suppliers who provide services to us (e.g. hotels for meetings and events, service providers for taxi transfers and flight bookings). In such cases, we only provide the information they need to perform the service or support required. Our service agreements with these third party suppliers contain data protection clauses to ensure consistency and compliance with this Privacy Policy and with the GDPR. Where service providers are located outside the EU, we ensure that adequate data protection measures are in place in the destination country, such as standard contractual clauses for data transfer as authorised by the European Commission.

We use a service called [Newsweaver](#) which we may use to send our newsletters and emails to you. [Newsweaver](#) is compliant with the GDPR; they will never email you or pass your details on to anyone else. In the future, we may change the emailing service we use and if we do so, we will ensure that it is a trusted service provider which is compliant with the GDPR.

8. How do we store your data?

Alzheimer Europe adopts industry standard, GDPR-compliant processes to ensure your data is kept safe and secure and to prevent unauthorised access or use or loss of your data. If you have any questions or concerns about this Privacy Policy or how we handle your information, please contact us at info@alzheimer-europe.org.

To ensure that we meet our legal data protection and privacy obligations, we only store your information for as long as we actually need it for the purposes it was acquired in the first place. After that we will either delete it or anonymise it so it cannot be linked back to you.

9. What are your data protection rights?

Alzheimer Europe would like to make sure you are fully aware of all of your data protection rights. These rights are not absolute and qualifications or restrictions can apply. We may charge a reasonable fee or refuse to comply with your request if it is unfounded, repetitive or excessive. We may also need to request specific information from you to help us confirm your identity and ensure your right to access your personal data.

Every user is entitled to the following:

The right to access – You have the right to request Alzheimer Europe for copies of your personal data. We may charge you a small fee for this service.

The right to correction - You have the right to request that Alzheimer Europe correct any information you believe is inaccurate. You also have the right to request Alzheimer Europe to complete the information you believe is incomplete.

The right to erasure - You have the right to request that Alzheimer Europe erase your personal data, under certain conditions.

The right to restrict - You have the right to request that Alzheimer Europe restrict the processing of your personal data, under certain conditions.

The right to object - You have the right to object to Alzheimer Europe 's processing of your personal data, under certain conditions.

The right to data portability – You have the right to request that Alzheimer Europe transfer the data that we have collected to another organisation, or directly to you, under certain conditions.

10. How to contact us

If you have any questions about Alzheimer Europe's privacy policy, the data we hold on you, or you would like to exercise one of your data protection rights, please do not hesitate to contact us in any of the following ways:

- by email: info@alzheimer-europe.org
- by post: 14, rue Dicks, L-1417 Luxembourg
- by phone: +352-29 79 70

11. How to contact the appropriate data protection authority

Should you wish to report a complaint or if you feel that Alzheimer Europe has not addressed your concern in a satisfactory manner, you may contact the National Commission for Data Protection of the Grand Duchy of Luxembourg (Commission Nationale pour la Protection des Données – CNPD)

NATIONAL COMMISSION FOR DATA PROTECTION

1, avenue du Rock'n'Roll, L-4361 Esch-sur-Alzette

Phone.: (+352) 26 10 60-1 | Fax.: (+352) 26 10 60-29

Opening hours: 09.00-12.30 & 13.30-17.30

For questions or comments, please use the form available on cnpd.public.lu, "contact"- section or send an e-mail to info@cnpd.lu