

ASI Privacy Statement Operations / Dementia Advisors / National Helpline



THE **Alzheimer**
SOCIETY OF IRELAND

Who are we? The Alzheimer Society of Ireland (ASI) is a company limited by guarantee and a registered charity in the Republic of Ireland (Registered charity number 20018238).

What do we do? ASI works within communities across the country providing dementia services such as day care, home care, respite, dementia advisors, support groups, social clubs and a national helpline. We process personal data (identifying information) and special category personal data (more sensitive data such as health information) to carry out this work. ASI is committed to adhering to data protection legislation and you can find the ASI Main Privacy Statement in the footer of our charity's website.

Who do we process data about? ASI Operations, Dementia Advisors and the ASI National Helpline process data about ASI service users, individuals with dementia or people with concerns related to dementia, carers or family members in order to provide health and social care services in the community or via the ASI Helpline.

What kind of data is processed by us? ASI processes different types of data depending on how and why you are interacting with us. ASI processes personal data and special category personal data for the purpose of providing health and social care services. We may process all or some of the following data to provide you with care, advice or support: Contact name, address, telephone number, email, health data, details for carer/family member/representative, photograph, life story, attendance records, update reports for carers and details of payments (if relevant). For safety reasons, we will document any incident or accident. We may capture your image if a CCTV security system is in place at an ASI managed location.

Where did we get your data from? We get your data when you or your carer, family member or representative, contact ASI to request that you become a service user. A health or social care professional may share your data with ASI by way of a referral.

How does the AS Helpline process data? The helpline usually collects personal data when you or your carer, family member, or representative contact the ASI helpline via phone, email, or live chat to request information on services available or to seek advice. However, phoning the helpline can also be done anonymously - helpline staff will not collect or store your details if you would prefer not to provide them. The ASI helpline does not record calls. Any recorded messages left to request a call back are listened to, noted and then deleted. Please be advised that the live chat system on the ASI website may automatically record your email address and IP address when you interact online.

What are our grounds for processing? In each instance that ASI Operations, Dementia Advisors and the ASI Helpline processes your personal data and/or special category personal data staff rely on one of the following legal grounds depending upon how or why you are interacting with us. Under GDPR there are six distinct legal basis for the processing of personal data (Art. 6) and a further ten distinct

legal basis for the processing of special category personal data e.g. more sensitive information such as health (Art. 9). ASI decides which legal basis is most suitable to align with each act of processing.

Purpose	Legal basis
Operations	<p>Legitimate interests (Art.6)</p> <ul style="list-style-type: none"> It is in the interests of ASI to efficiently and effectively manage our day care, day care at home, home care, dementia advisors, social clubs and helpline services for service users or carers and ensure compliance with duties of care and other obligations. <p>Performance of a contract (Art.6) Compliance with a legal obligation (Art.6) Provision of health and social care (Art. 9) Vital Interests (Art. 9) Association / Not-for-profit organisation (Art. 9) Employment & Social Security (Art.9)</p>
Helpline	<p>Legitimate interests (Art.6)</p> <ul style="list-style-type: none"> It is in the interests of ASI to provide a national helpline to provide support and information to persons with dementia and their families and carers. <p>Compliance with a legal obligation (Art.6) Vital Interests (Art. 9) Provision of health and social care (Art. 9) Association / Not-for-profit organisation (Art. 9)</p>
Safety & Security	<p>Legitimate Interests (Art.6)</p> <ul style="list-style-type: none"> It is in the interests of the organisation to install CCTV systems when deemed necessary and proportionate and to process data about health and safety issues for the purposes of seeking legal advice or insurance risk assessments <p>Compliance with a legal obligation (Art. 9) Defence of legal claims (Art. 9) Vital Interests (Art. 9)</p>

How long do we retain your data? ASI keeps personal data and special category personal data for a range of periods. The ASI retention schedule, which is reviewed annually, details current policies which are based on:

- Statutory obligations such as requirements issued by Revenue.ie for financial records to be retained (6 years)
- Contractual obligations such as requirements from the HSE under service level agreements for client records to be retained (8 year from last contact);
- Quality assurance / best practice obligations set by state entities or regulatory bodies such as requirements under Health & Safety legislation to retain incident records (10 years);
- For reasonable periods after the conclusion of engagements for quality assurance and risk management purposes such as ASI QSPD audits of ASI service locations (10 years).
- ASI’s view that retention is necessary for the original purpose or a compatible purpose such as retaining training records for an external individual (5 years from completion of last training module);

On a case-by-case basis, records may be retained for longer where they are required for actual or potential legal actions or the management or mitigation of operational or strategic risks to the

organisation. Where records are subject to this kind of review the ongoing retention will be assessed annually.

Where do we keep your data? Sector leader service providers have been contracted and ASI data, in digital form, is stored in data centres in Ireland. All back up servers are located inside the EU. ASI IT oversee key security and usage procedures and policies relating to information security and devise clear instructions for staff. Hard copy records are also maintained by ASI. All sensitive files are stored in locked cabinets and secure rooms with restricted access.

Do we share your data? In the context of service provision, ASI health and social care professionals may share your data with external health or social care professionals, or with a relevant medical or care facility, including with HSE staff, in order for you to receive the best standard of care. We may be legally obliged to share your data with state entities, e.g. for financial compliance. Relevant categories of recipients may include the tax authorities, government departments, law enforcement and regulatory bodies. ASI receives HSE funding under Section 39 of the Health Act 2004 and as a result may be contractually obliged to share certain data. ASI will always prioritise your privacy by considering whether the sharing of pseudonymised or anonymised data would be sufficient in the circumstances. ASI also contracts third party service providers to manage and store personal data. These situations are managed by data processor agreements which contain clear contractual safeguards. Please note that ASI health and social care staff are trained to respond in an emergency. If they believe you may be in danger they will share your personal data to ensure your safety.

What are your rights? Individuals have rights over their personal data under EU and Irish Data Protection law. These rights are not absolute, and qualifications or restrictions can apply. The most exercised right by individuals is the right of access. This is the making of a request by a data subject, which gives them the right to obtain – subject to certain restrictions provided for under the GDPR and the DPA 2018 – access to, and copies of, their own personal data, and other relevant information, free of charge and in an accessible form. A data controller must ensure that individuals whose data they are processing are facilitated in lodging access requests. A data controller must provide a response to an access request in a certain manner and within a certain time.

In summary, the rights that can be exercised by data subjects under data protection law also include: the right to be informed; right to rectification; right to be forgotten / erasure; right to restrict processing; right to object; right not to be subject to automated decision making and/or profiling; right to portability and the right to withdraw consent at any time. ASI is committed to helping individuals exercise their rights over their own data. Please contact the ASI DPO as set out below to exercise any of these rights or for further information. If you believe your data privacy rights have been infringed by ASI, you have the right to make a complaint to the Data Protection Commission using the contact details below. It may also be possible to seek compensation through the courts.

How can you contact the ASI Data Protection Officer? You can contact the ASI DPO by email: dataprotection@alzheimer.ie or by post: DPO, Alzheimer Society of Ireland, National Office, Temple Road, Blackrock, Co. Dublin, A94 N8Y0. Telephone: (01) 2073800

You can contact the Irish data protection regulator, the Data Protection Commission by webform on its website www.dataprotection.ie by email: info@dataprotection.ie or by post: 21 Fitzwilliam Square South, Dublin 2, D02 RD28 and Canal House, Station Road, Portarlinton, Co. Laois, R32 AP23. Telephone (01) 765 01 00 / 1800 437 737

ASI updates this Privacy Statement periodically. Updates will be made available and, where appropriate, notified to you. Privacy Notice dated: October 2024