

Dementia Active

Confidentiality, Privacy & GDPR Policy

WEBSITE WORDING UPDATE - 12 October 2026

1. Purpose

Dementia Active is committed to protecting the privacy, dignity and personal information of everyone who uses, works with or supports our service. This policy explains how Dementia Active handles confidential information and personal data in line with UK GDPR, the Data Protection Act 2018, confidentiality duties and safeguarding practice.

This final merged version incorporates Dementia Active's website privacy policy and staff / volunteer privacy notice, while keeping the broader confidentiality and GDPR controls needed for day-to-day service delivery.

2. Scope

This policy applies to staff, volunteers, trustees, contractors, sessional workers and anyone acting on behalf of Dementia Active. It applies to information held in any format, including paper records, online forms, Jotform, emails, phones, spreadsheets, photographs, video, messaging apps, payroll systems and verbal conversations.

- People living with dementia who attend groups, sessions or activities.
- Family members, carers, relatives, friends and emergency contacts.
- Staff, volunteers, trustees, contractors and applicants.
- Referrers, funders, donors, supporters, professional partners and members of the public.
- Organisations that invite Dementia Active CIC or CIO to run a session.

3. Who we are and controller status

Dementia Active CIC is the data controller for registration, participant and member information, including enquiries submitted through the Didcot interest form. The CIC decides why and how this information is collected and used. All donations go to Dementia Active CIO. Necessary sharing of member, financial and Gift Aid information with the CIO is described in section 12a.

For questions about registration or member information, contact Dementia Active CIC using the contact details in section 4 and ask for the person responsible for data protection.

4. Contact details

Dementia Active, 7 Manor Park, Jugglers Close, Banbury, Oxfordshire OX16 3TB

Telephone: 01295 408441

Email: info@dementiactive.co.uk / dementiactive@gmail.com

5. Confidentiality

All staff, volunteers, trustees and representatives of Dementia Active must treat personal, sensitive and organisational information as confidential. Confidential information must only be accessed, used or shared where there is a proper reason connected to the person's role or Dementia Active's lawful responsibilities.

Confidential information must not be discussed in public places, with friends or family, on personal social media, or with anyone who is not authorised to know it. The duty of confidentiality continues after a person stops working or volunteering with Dementia Active.

6. Personal information we collect

Dementia Active may collect and use the following types of information where relevant and necessary:

- Name, address, email address and telephone numbers.
- Date of birth, emergency contacts, carer/family/relative/friend details and communication preferences.
- Information provided on sign-up forms about a relative or friend attending a Dementia Active group.
- Health, mobility, medication, allergies, dementia-related needs, support needs and wellbeing information.
- Attendance, activity, transport, risk assessment, incident, accident, complaint and safeguarding records.
- Bank or payment details where GoCardless or another payment route is used.
- Photographs, video and publicity information where appropriate permission has been given.
- Staff and volunteer recruitment, role, contract, training, payroll, pension, tax, bank, leave, sickness, wellbeing, occupational health, reference and accident-at-work information.

7. How we get personal information and why we have it

Most personal information is provided directly by the individual, a relative, friend, carer, staff member, volunteer, referrer or partner organisation. Participant information is collected so Dementia Active can support the person safely and appropriately in a Dementia Active group.

Dementia Active uses personal information to provide safe and person-centred activities, manage attendance, support needs, transport and emergency arrangements, communicate with carers and families, meet safeguarding responsibilities, manage staff and volunteers, process payments where applicable, keep records required for insurance, funding, monitoring and governance, and respond to complaints, incidents or legal obligations.

Dementia Active will not share personal information with another organisation or individual without permission unless there is another lawful and necessary reason, such as safeguarding, legal obligation, vital interests, insurance, emergency response or prevention of serious harm.

8. Lawful bases for processing

Dementia Active will identify an appropriate lawful basis before processing personal data. Depending on the situation, this may include:

- Consent - for example, certain photographs, video, publicity stories or non-essential communications.

- Contract - where information is needed for employment, volunteering, service, payment or other arrangements.
- Legal obligation - for health and safety, employment, tax, safeguarding, charity governance, accounting or regulatory duties.
- Vital interests - in an emergency where someone's life, health or safety may be at risk.
- Legitimate interests - where Dementia Active has a reasonable need to use information to run safe and effective services and this does not override individual rights.

9. Special category data

Health, wellbeing, dementia-related information and some staff health information are special category data and require additional protection. Dementia Active will identify both a lawful basis under UK GDPR Article 6 and a special category condition under Article 9 where required. This may include explicit consent, provision of health or social care, employment obligations, vital interests, safeguarding, legal claims or another relevant condition.

10. Consent

Where Dementia Active relies on consent, consent must be freely given, specific, informed, clearly recorded and easy to withdraw. Withdrawal of consent will be respected unless there is another lawful reason to continue using the information, such as safeguarding, legal duties, insurance or vital interests.

Consent should be reviewed where someone's circumstances, capacity, family arrangements or wishes change. Staff and volunteers must be alert to dignity, capacity and safeguarding issues when relying on consent.

11. Photographs, video and publicity

By signing up for a Dementia Active session, signing up as a volunteer or staff member, or inviting Dementia Active CIC or CIO to run a session, individuals may be asked to give permission for photographs or video taken by Dementia Active to be used in social media content, promotional materials and publicity efforts where the participants are over the age of 18.

Photographs and videos may be used in publications, printed promotional materials, direct mail, electronic media, the internet, websites, social media or other forms of promotion. Dementia Active should record clear consent for identifiable photographs, video and personal stories and should explain what the material may be used for, where it may appear, that consent can be withdrawn, and any practical limits on removing material already printed, distributed or published by third parties.

People must not be pressured to appear in photographs, videos or publicity. Particular care must be taken with people living with dementia, including capacity, best interests, distress, dignity and family/carer concerns.

12. Information sharing

Dementia Active will only share personal information where there is a lawful and necessary reason. Information may be shared with express permission, or without consent where required by law, for safeguarding, to prevent serious harm, in an emergency, or to meet a legal or insurance requirement.

Only the minimum necessary information should be shared, and sharing should be recorded where appropriate. Information may be shared with:

- Emergency services.
- Health and social care professionals.
- Local authorities and safeguarding teams.
- Transport providers where needed for safe travel.
- Training suppliers, HMRC, payroll/pension providers and employee benefit schemes.
- External auditors, funders, regulators, insurers, legal advisers and professional advisers where necessary.
- GoCardless or another payment processor where the individual chooses or is required to use that payment route.

12a. Jotform privacy and data handling policy

This policy governs information collected through Jotform forms operated by Dementia Active CIC. It protects members, carers and others whose information we receive, and sets the access and sharing rules staff and volunteers must follow. It supplements the CIC's main privacy notice and related safeguarding and retention policies.

1 Responsibility for information

Dementia Active CIC is the data controller for the forms it operates: it decides what information is collected and why and how it is used. Jotform provides the form platform and acts as a data processor for these submissions. Jotform has separate responsibilities for information it collects for its own purposes, such as website usage and account administration, as explained in its privacy policy. [1]

2 Information collected and permitted purposes

Forms must request only information necessary for their stated purpose. Depending on the form, this may include member and carer contact details, emergency contacts, relevant health and support needs, transport arrangements, and information needed to administer donations. Each form must explain its purpose and link to the relevant privacy information.

Before collecting or sharing information, the CIC must record the applicable lawful basis under Article 6 of the UK GDPR. Health information also requires an applicable Article 9 condition and any associated Data Protection Act 2018 safeguards. Submitting a form does not by itself establish valid consent. Staff must check a representative's authority where relevant and must not assume a family relationship permits consent on another person's behalf. [5]

3 Access by CIC staff

Access to Jotform submissions is restricted to authorised CIC staff who need the information for their duties, subject to the limited sharing and technical processing described in this policy. Staff must access only the records necessary for their work. Full submissions, attachments, tables and reports must not be made generally available to the charity or its volunteers.

Managers must approve access, review it regularly and remove it promptly when duties or

employment change. CIC access must be reviewed when a person moves to employment with the charity; previous CIC employment does not give continuing access rights.

4 Limited sharing with Dementia Active charity

Dementia Active CIC shares relevant Jotform information and Gift Aid records with authorised personnel of Dementia Active CIO only as and when necessary to collect, reconcile and administer donations and Gift Aid. Only the information needed for that purpose is shared. This may include a member identifier, donor name and contact details, donation amounts or payment status, and the relevant Gift Aid declaration and supporting records.

The charity must not receive complete Jotform submissions, detailed care records or unrelated information for donation administration. Data sharing arrangements must record the purpose, permitted information, each organisation's responsibilities, security requirements and retention arrangements. Any information that reveals or allows an inference about health must receive the appropriate additional protection.

5 Limited sharing with charity volunteers

Authorised charity volunteers may receive only the member details strictly necessary for their assigned duties and to support members safely. For example, a volunteer driver may need collection details and essential mobility or safety instructions. The information provided must reflect the task and must not include a full member record where a limited extract will suffice.

Volunteers must maintain confidentiality, use information only for the authorised purpose, follow the CIC's secure handling instructions and return or securely delete it when no longer required. They must not forward it, retain it for personal use or disclose it to unauthorised people.

6 Jotform and its service providers Jotform Inc. is based in the United States. Its platform receives and stores form submissions on our behalf. Jotform and its authorised subprocessors may need to process or access information to provide hosting, security, maintenance and support. This processing is additional to access by CIC staff and the limited charity sharing above. Jotform publishes information about its subprocessors and says it does not sell customers' form data. [1, 3]

The CIC must retain an applicable Data Processing Addendum with Jotform and assess relevant subprocessors and features. Staff must not enable new integrations, AI features, automated forwarding or external access without a documented privacy and security review and management authorisation. [2, 3]

7 Storage outside the United Kingdom

Jotform's published guidance states that data is usually stored in the United States, with alternative regions available by arrangement. The CIC must establish and record its actual storage region. Storage in the UK or EU does not by itself rule out overseas access or legally required disclosure. [1,2]

Where a restricted international transfer occurs, the CIC must establish a valid UK transfer mechanism. Jotform states that it uses Standard Contractual Clauses with the UK Addendum for UK transfers. The CIC must check the applicable agreement and complete any required transfer risk assessment, also called a data protection test, including additional safeguards where necessary. It must

not assume that Jotform's US location or a general compliance statement settles these requirements. [2, 4]

8 Security and confidentiality

Staff must use individual authorised accounts where available, strong passwords and multifactor authentication where supported. Shared passwords, public submission links and unapproved storage must not be used. Sensitive form answers must be excluded from routine email notifications where possible; staff should access the protected record instead. Downloads, printouts and approved extracts remain subject to this policy. Information must be shared through approved secure methods. Staff must check recipients and permissions before sending it, protect devices against unauthorised access and report misdirected messages, lost devices or suspected breaches immediately to the CEO or designated responsible manager. The CIC must assess incidents promptly and make any notifications required by law.

9 Necessary legal and safeguarding disclosures

Information may be disclosed where required by law or where necessary and lawful to protect an individual, respond to a safeguarding concern or assist emergency services. Only relevant information may be disclosed. The reason, recipient and lawful basis must be recorded, with management involvement wherever practicable. Urgent protection must not be delayed by routine internal approval processes.

Jotform may also be required to disclose information in response to valid legal demands. No promise is made that information can never be accessed outside the CIC. [1, 2]

10 Retention and deletion

The CIC must assign a documented retention period or clear retention criteria to each form and record type, reflecting service needs and legal requirements. Records must be reviewed and securely deleted when no longer required, subject to any necessary legal hold. This applies to submissions, attachments, exports, notifications and copies shared with the charity or volunteers. Relevant provider backup and deletion arrangements must also be checked.

11 Individual rights and enquiries

Individuals may contact Dementia Active CIC to ask about their information or exercise applicable data protection rights, including access, correction, erasure, restriction, objection and portability.

These rights depend on the circumstances. Where consent is relied on, it may be withdrawn without affecting earlier lawful processing. Identity and representative authority must be checked

appropriately. Contact Dementia Active CIC using the contact details in its main privacy notice and ask for the person responsible for data protection. Individuals may also complain to the Information Commissioner's Office at ico.org.uk/make-a-complaint/.

12 Oversight and review

The CEO is responsible for ensuring this policy is implemented and reviewed annually, and sooner if services, staffing arrangements, Jotform features, subprocessors or relevant law change.

Research sources

Official provider information and ICO guidance checked on 13 September 2026. Provider statements describe its published position; account specific arrangements remain to be verified.

[1] Jotform Privacy Policy

[2] Jotform Data Transfer Impact Assessment

[2] Jotform Data Processing Addendum

[3] Jotform Subprocessors

[4] ICO International transfers

[5] ICO Special category data

13. Systems and storage

Participant information may be securely stored on the Jotform platform. Dementia Active may also use email, paper records, phones, spreadsheets, payroll systems, accounting records and other approved systems. Dementia Active will protect personal information by:

- Keeping paper records in locked storage.
- Using password protection, access controls and secure devices.
- Limiting access to people who need the information for their role.
- Avoiding unnecessary printing or duplication.
- Using secure email, password-protected documents or secure portals where appropriate.
- Not leaving records visible in vehicles, public spaces or activity venues.
- Not using personal email, personal cloud storage or unapproved apps for service-user information unless specifically authorised.

14. Data retention and disposal

Dementia Active will not keep personal information for longer than necessary. Information will be securely deleted, shredded or anonymised when no longer required. Participant information is normally kept for as long as the relative/friend remains a member of Dementia Active and is then deleted from Jotform, unless Dementia Active needs to retain limited records for legal, safeguarding, insurance, complaint or governance reasons.

Record and Retention approach

Participant registration, sign-up and membership information -

Keep while the person is a member or receiving support, then delete or archive only what is necessary for legal, safeguarding, insurance or complaint purposes.

Emergency, health, dementia-related and support information -

Review regularly and update promptly; delete or archive when no longer needed, subject to safeguarding, legal and insurance requirements.

Incident, accident and complaint records -

Usually at least 3 years, or longer where safeguarding, insurance, legal or unresolved complaint issues require it.

Safeguarding records -

Retain in line with safeguarding guidance and risk; keep longer where concerns are ongoing or may need future reference.

Staff and volunteer files -

Up to 6 years after the person leaves, in line with the staff / volunteer privacy notice.

Payroll, pension, tax and financial records -

Usually 6 years or as required by tax, accounting, pension or charity law.

Photograph / video consent records -

Keep while the relevant image, video or story is in use, then delete or archive appropriately.

Marketing and publicity contacts -

Keep until consent is withdrawn, the contact unsubscribes, or the information is no longer active or needed.

15. Data breaches

A personal data breach may include sending information to the wrong person, losing paperwork or a device, unauthorised access, accidental deletion or alteration, or inappropriate verbal disclosure.

All suspected breaches must be reported immediately to Andrew Gill or the designated manager/data protection lead. Dementia Active will assess the breach, take action to reduce harm, record what happened and, where legally required, report it to the ICO and/or affected individuals.

16. Data protection rights

Individuals have rights under data protection law. These include:

- The right to be informed about how their information is used.
- The right of access - to ask for copies of personal information.
- The right to rectification - to ask for inaccurate or incomplete information to be corrected.
- The right to erasure - to ask for deletion in certain circumstances.
- The right to restriction of processing - to ask Dementia Active to limit how information is used in certain circumstances.
- The right to object to certain processing.
- The right to data portability in certain circumstances.
- The right to withdraw consent where consent is the lawful basis.

17. Subject access and rights requests

Requests should be passed to Andrew Gill or the manager/data protection lead as soon as possible. Dementia Active will respond without undue delay and in any event within one month unless an extension is permitted by law.

To make a data protection rights request, contact Dementia Active using the contact details in section 4.

18. Safeguarding and confidentiality

Confidentiality must never be used as a reason to ignore abuse, neglect or risk of harm. If staff or volunteers have a safeguarding concern, they must report it immediately to the Dementia Active safeguarding lead or manager in line with the Safeguarding Policy.

Information will be shared on a need-to-know basis with appropriate professionals or authorities.

19. Staff and volunteer privacy notice

When someone works or volunteers for Dementia Active, personal information may be collected and used to manage their role, keep records, make salary, pension or expense payments, provide training, manage wellbeing and meet legal duties.

This may include job role, contract details, start and leave dates, salary, working patterns, timesheets, expenses, overtime, leave, sick leave, maternity, paternity, shared parental and adoption leave and pay, pension details, bank account details, payroll records, tax status, general health and wellbeing information, occupational health referrals and reports, fit notes and accident at work records.

Lawful bases may include consent, contract and legal obligation. Health and wellbeing information may also require a special category condition. Staff and volunteer information is usually kept for up to 6 years after leaving, unless a longer or shorter period is justified.

Information may be shared with training suppliers, HMRC, payroll providers, pension providers, employee benefit schemes, external auditors, insurers, legal advisers and professional advisers where necessary.

20. Staff and volunteer responsibilities

All staff, volunteers and trustees must:

- Read and follow this policy and relevant privacy notices.
- Keep personal information confidential and secure.
- Only access information needed for their role.
- Not share passwords or login details.
- Report data breaches, confidentiality concerns and safeguarding concerns immediately.
- Complete relevant training where required.
- Ask for guidance if unsure whether information can be used or shared.

21. Working away from premises

When working off-site, travelling or running community sessions, staff and volunteers must carry only the information needed, keep paperwork and devices secure, avoid confidential conversations where they can be overheard, return records to secure storage promptly and avoid personal email, personal cloud storage or unapproved messaging apps for confidential information.

22. Training and awareness

Dementia Active will provide appropriate guidance or training on confidentiality, data protection and safeguarding. Training will be refreshed where necessary, especially where roles, systems, services or legal requirements change.

23. Complaints and ICO contact

Anyone with concerns about Dementia Active's use of personal information can contact Dementia Active at Dementia Active, 7 Manor Park, Jugglers Close, Banbury, Oxfordshire OX16 3TB, by telephone on 01295 408441, or by email at info@dementiactive.co.uk / dementiactive@gmail.com. Dementia Active will acknowledge a data protection complaint within 30 days of receipt, make appropriate enquiries without undue delay, keep the complainant informed about progress and communicate the outcome. A complaint may be made by email, telephone, post or through our complaints form; use of the form is not required.

If a person remains unhappy, they can complain to the Information Commissioner's Office:

ICO address

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF

ICO helpline

0303 123 1113

ICO website

ico.org.uk/make-a-complaint

24. Policy ownership and approval

Policy owner - Andrew Gill

Approved by - The Trustees

Contact details -01295 408441 / info@dementiactive.co.uk / dementiactive@gmail.com

Responsibilities - Data protection questions, privacy notices, subject access requests, breach reporting, retention and deletion, staff and volunteer guidance, and privacy queries from members, relatives, carers and partners.

25. Website privacy notice summary

Dementia Active's website privacy notice should be kept consistent with this policy. The public-facing notice should clearly explain who Dementia Active is, what personal information is collected, how it is obtained, why it is used, lawful bases, retention, rights, complaints, ICO contact details and any third-party platforms such as Jotform and GoCardless.

Where the website includes a staff / volunteer privacy notice, it should also cover salary, pension, payroll, tax, leave, wellbeing, occupational health, accident at work records, lawful bases, retention, sharing with HMRC/training suppliers/benefit schemes/auditors and clear identification of the organisation responsible for each category of staff and volunteer information.

26. Policy review

This policy will be reviewed at least annually or sooner if legislation, ICO guidance, Dementia Active services, systems, website wording, contracts or data handling practices change.

The policy should also be reviewed following any serious data breach, safeguarding issue involving information sharing, significant complaint or introduction of a new system.

Andrew Gill : 08/06/2026 Review date : 07/06/2027

Website complaints wording clarified: 12/10/2026. This clarification does not replace the recorded trustee approval or confirm a review of operational data arrangements.

Controller and information-sharing wording updated: 12/10/2026. The recorded approval and review dates above are retained; this website wording update is not a new trustee approval record.