



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia

# Volunteer Data Protection 2025 Workbook

This module covers the Data Protection learning needed by volunteers in specified volunteer roles.

# 1. Introduction

This training is for volunteers who use data in their role and builds on the learning you should have already done in Part 2 of Welcome to Alzheimer's Society. It's really important we all know how to look after data we use in our roles, whether it's confidential information about people, the Society or research.

Even if in your volunteering role you feel like some parts of this module don't apply directly to what you do, please read each section and try to think about how you might apply the principles to your role.

**When you have completed this workbook, you should be able to:**

- Know how you can find guidance, standards, information and advice about handling personal and confidential information in your volunteer role.
- Recognise what personal and other confidential information is, understand why it's important to handle personal information securely in your role and how you do this.
- Know what to do if you have concerns about how personal or other confidential information is used in activities you support, including how to identify what might be an incident and who to report it to.

**Note:**

There will be exercises to complete along the way so make sure you have a pen and paper nearby to write down notes as you go.

**When you are finished**, contact your role manager. They will discuss the workbook with you and then update your record to show you have completed it.

**Let's get started!**

## 2. Data protection overview

### Protecting data

At Alzheimer's Society, protecting people's personal information is the foundation of the trusted relationships we have with our service users, supporters, research participants, employees and volunteers.

In the UK there are data protection laws and regulation to protect everyone's personal information and make sure that organisations use it fairly and lawfully. The [Data Protection Act 2018](#) and [UK General Data Protection Regulation \(UK GDPR\)](#) - and the equivalent in the Channel Islands - set out what is needed to use and protect people's information in an appropriate way.

As a volunteer who has access to people's information, it's important you understand what requirements there are, and how to keep the personal information you access, see, hear or use in your role safe and protected. We must make sure that personal information is kept safe and secure at all times – including when collected, transported between locations, stored, shared with others and deleted.

We review every volunteer role to identify if the role needs to handle people's information and how we can help you to keep it safe and secure - for example access to certain systems, keeping notes that are anonymised, or a lockable bag for transporting paper records between locations. If you think you might not have everything you need to manage and protect personal information you may handle in your volunteer role, please speak with your role manager.

### Other guidelines

As well as this training, Alzheimer's Society has policies, standards, guidelines and procedures which help our people understand how to comply with UK data protection laws.

Your role might include supporting people, organising information or helping at events. You may hear or see personal information that you don't need to collect, record, share or transport. It's important to build confidence about what information you do need to use or share, and when it's good to anonymise information. As your role has been assessed as using personal data, for example if you email information about service users or record information about supporters, the below policy and standard can be found in the [Volunteer Portal](#). Please ask your Role Manager for support in accessing if you need it.

- [Information Management Policy](#)
- [New Information Management Standard](#) which helps you understand how to meet the Policy requirements

## 3. Personal information we store, handle and process

### Sharing data

We live in an increasingly data-driven world. Information is continually being created by combining data, often from multiple sources, to make it useful. You may not always realise how much information organisations are collecting and using about you.

Sometimes it's clear what information you're sharing and how it might be used, and by whom. But you may also share personal information you're less aware of, for example, every time you visit a website, search online, or use social media.

Sharing this information can sometimes help make life easier and more convenient. But you may not always want your information shared.

**It's your personal information and you should be able to control it. And here at the Alzheimer's Society we need to respect the personal data we use.**

### Reminder

You might remember from your induction learning that personal data is defined as **"information which relates to someone - a living individual who can be identified from the information"**.

It could be a name on a register, an email address, or a picture of someone.

It could also be **sensitive information** including details about religious beliefs, race, health conditions or sexual orientation.

## Activity

Think of a piece of your own personal information that you have either shared or may need to share with your role manager. It could be something which is simply personal information, or it could fall into one of the special categories of personal information. You don't need to actually share this information, just bring it to mind for the purposes of this activity. There is space below to write it down if you would like to.

Make a note below.



How would you feel if this piece of information was left somewhere, or shared with someone who didn't need it? For example, if it was in a notebook left in a coffee shop or you heard the person telling someone else something private you had shared with them?

How would you feel if they used it for a different reason than the one they had told you about?

How would you feel if the organisation you gave your information to didn't ensure your information was kept safe and secure? For example, in the way they stored it on their systems, sent it to others who needed it, or deleted it when no longer required.

**You probably wouldn't feel great, and you might well be angry, worried or disappointed.**

Now let's have a look how this impacts people who use Society services or support us...

## Information about people affected by dementia

We need to understand people's experiences to provide the kind of support they want, need or deserve, and to help raise awareness of dementia.

**This will include personal information.** We are privileged to receive this information and we must treat it with the respect it deserves.

## Personal information you use in your role

The personal information we receive as volunteers will vary depending on the activities and responsibilities involved in our role. Take a moment to think about your volunteer role and what personal information you may know about the person you are supporting. Feel free to jot down

**Let's think about who you may meet in your role.**

Below you will find 3 different situations. Once you have read through each, ask yourself the following questions and jot down any thoughts:

- What personal information might people give us?
- What other personal or confidential information do you think Alzheimer's Society is likely to hold and where do you think this information may be stored?

**1) Someone coming to our event with access needs**

**2) Someone applying for research or new product support**

**3) Someone we support**

Compare the notes below with the notes you made:

<p>Someone coming to our event with access needs</p>	<p><b>Personal Information</b></p> <ul style="list-style-type: none"> <li>• Name</li> <li>• Phone Number</li> <li>• Emergency Contact information</li> <li>• Support needs</li> <li>• Equality monitoring information (for example ethnicity, gender)</li> </ul>	<p><b>Where is the information stored</b></p> <ul style="list-style-type: none"> <li>• Application or booking form</li> <li>• Attendance sheet</li> <li>• Alzheimer's Society systems for services, events, volunteer and staff</li> </ul>
--	--	--

<p>Someone applying for research or new product support</p>	<p><b>Personal Information</b></p> <ul style="list-style-type: none"> <li>• Name</li> <li>• Contact details: phone number, email address, address</li> <li>• Place of work</li> <li>• Qualifications or experience</li> </ul> <p><b>Other personal or confidential information</b></p> <ul style="list-style-type: none"> <li>• Financial information</li> <li>• Research or product proposal</li> </ul>	<p><b>Where is the information stored</b></p> <ul style="list-style-type: none"> <li>• Application form</li> <li>• Alzheimer's Society systems for applications</li> <li>• Email account</li> </ul>
---	--	---

<p>Someone we support</p>	<p><b>Personal Information</b></p> <ul style="list-style-type: none"> <li>• Name</li> <li>• Contact details: phone number, address and email address</li> <li>• Emergency contact information</li> <li>• Family names and information</li> <li>• Date of birth</li> </ul> <p><b>Other personal or confidential information</b></p> <ul style="list-style-type: none"> <li>• Support needs</li> <li>• Dementia Diagnosis</li> <li>• Equality monitoring information (for example ethnicity, gender)</li> <li>• Service use record</li> </ul>	<p><b>Where is the information stored</b></p> <ul style="list-style-type: none"> <li>• Referral form</li> <li>• Alzheimer's Society systems for service users</li> </ul>
---------------------------	---	--

As you can see, the Society collects and uses lots of information about people but only what's needed for each service or function.

**Make sure you know your local procedures for using people's information in the right way.**

## 4. Why it's important we get it right

### It's a matter of trust

If we don't manage information properly we are putting the Society's reputation at risk, having an impact on the ability to attract supporters and donors.

### It's also the law

We have legal responsibilities to handle personal information properly.

**Failure to comply can be a criminal offence and could result in heavy fines or prosecution for the Society.**

Getting it wrong could significantly reduce the support and services we offer to people affected by dementia, and our ability to fund vital research.

We all need to be conscious and aware when handling personal information. We must be sure we are using it correctly and legally.

In the next section we'll look at some simple tips to help you handle information the right way.



## 5. How to keep information safe

There are many ways the Society uses good information and cyber security protective measures.

If you have a Society email account or access to our systems, some of the protective measures are managed in the background by the IT team.

If you use your own personal email account to receive information from the Society and your role manager, the advice in this section can still protect the Society and the people we support from security risks. As well as help to protect your own personal data unconnected to your volunteer role at the Society.

**Please note you shouldn't use your own devices (mobile phone, tablet, or laptop) to save any personal or confidential data you might need to use or store for your role. Remember this also includes photos. Pictures or information relating to service users, supporters, employees or other volunteers should only be stored within Alzheimer's Society systems or devices.**

[In this section you can find advice on what to consider so you can play your part in keeping people's information safe. These apply to volunteer roles whether you travel to different locations, to an office or are based at home.](#)

### Confidentiality

We must take care with how we use, share and talk about information when we're at an event, office, at home, and on the move so people who aren't entitled to see or hear it can't do so. Think carefully about your surroundings and keep conversations, device screens and paperwork to yourself.

If there is a need in your role to keep or make paper records then firstly consider whether you can anonymise them - for example making notes during a call or conversation with a service user, just use the service user's initials.

If notes can't be anonymised, make sure they're securely stored while you need to keep them, then securely destroyed. They can be taken to a Society office to be put in the confidential waste or in some circumstances your Role Manager may advise you on other ways to securely destroy the information.

If you travel between locations with paper records containing personal or confidential data or need to store such records at home for a period of time speak to your Role Manager about whether you need a lockable bag and/or cupboard.

### Data Sharing

All information in the Society is classified as either **Public**, **Official**, or **Official Sensitive** as specified in the Handling Information section of the Information Management Standard. Always consider the classification of information you are working with before sharing it, to make sure that you share it with the right people in the right way.

The Information Management Standard also includes principles for you to follow when making decisions about sharing information. Key elements are that:

- You must have a valid reason to share it **and** the recipient must have a need to know it.
- Anonymise information where possible.
- The person who the information is about should usually have been told it will be shared, with whom and why.

## Data Security

Email security is very important and there are tools that should be used to keep information safe. When sending personal or other confidential information to an external email address, you should encrypt the email or ensure attachments are password protected. This includes data which may be sent to you from your role manager.

You should also keep aware of phishing scams and make sure you don't click on any links if you're not sure who they came from. If you have any concerns our IT helpdesk can help.

**To help you handle information safely remember:**

**'Stay **SECURE** and be **S.U.R.E**'**

**Stop and think** about whether a recipient needs and is allowed to have information you may be about to share

**Understand** the process you should be following or what classification the record has to help you decide how to protect it

**Review** what you are about to do / send / share to make sure it is correct

**Expert advice:** if you're not sure, speak to your Role Manager who can contact the Information Governance team if they need further advice themselves

**It's not just your role manager who can help...**

**Connect with other volunteers and share best practice in conversations, at events, or at groups.**

## Keeping aware is the best step to preventing issues.

Think about the following tips to help you:

### Protect paper records in transit

If you have to carry paper records between locations, such as attendance lists from an activity back home to type them into Society systems, make sure you use a lockable bag.

If using public transport keep the bag with you at all times and if you're travelling by car, keep the bag out of sight (for example in the boot) and don't leave the vehicle unattended unless in an emergency.

### Check emails you are about to send have the right person's email address

Emails often automatically add email addresses when you start to type one in. This is great, so long as you check it is the right person! Double check the right people have been added. You can delete from the automatic list, any emails that you won't contact again. If you think this is a large risk for you, you can turn off the automatic list altogether.

### When sending personal information externally make sure it is appropriately protected

Before sending personal or confidential information check the Handling Information section of the Information Management Standard on the Volunteer Portal and make sure the right level of security is used.

For example, when sending service user data to your Role Manager always make sure you use your Alzheimer's Society email so it is sent securely. If you need to send personal or confidential information to someone outside the Society, make sure it is sent encrypted using your Alzheimer's Society email. Ask your Role Manager if unsure.

### For email, use 'bcc' if people don't need to know each other's email addresses

If you're emailing people who haven't agreed to share their email addresses with others, use the blind carbon copy (bcc) function. Before sending, always check the 'to'/'cc'/'bcc' fields and make sure you have selected the right people in the right fields.

### Don't assume it's ok to share personal information

For example, if you make calls in your volunteering role, don't leave messages with details of what you're calling about as someone else may hear or pick up the message who isn't entitled to know that information.

Stop and think before you share personal or confidential details with anyone else, including family members. If unsure check with your Role Manager. Don't assume personal information is shared with all family members.

### For any notes – only include facts, not opinions

Make sure any notes you make on our systems or in emails only give factual information e.g., email with a concern about someone, activity notes, or points for a session debrief. This helps show respect to the person involved. An example of this is emailing a concern about a person saying "they seemed unsteady on their feet and had slurred speech". This is factual information rather than a comment like "they seemed drunk" which is an opinion.

Remember people have a right to copies of information we hold about them. This can include anything that's been written down about them.

**Stop and think! A lot of incidents happen at busy times so make S.U.R.E to take the time to get it right**

The Society has had to report incidents to the regulator where employees and volunteers have shared personal information with someone where it wasn't necessary to do so. The investigation revealed that the sharing wasn't lawful in these cases.

**Always be S.U.R.E. when handling any information that could identify an individual.**

**If in doubt, always ask for advice and guidance before you take action!**

## 6. Reporting incidents

### If something goes wrong

We are all human and things do go wrong - the important things are that you notice and take action - **time is of the essence** when people's information hasn't been kept safe

#### Act quickly

If you notice that something has gone wrong relating to personal or confidential data, you must tell your role manager **immediately** as they will need to complete an Information Governance (IG) incident reporting form and send it to the IG team **straight away**.

Organisations only have **72 hours** to report serious personal data protection breaches to the privacy regulator, the Information Commissioner's office in the UK.

The 72 hour timescale includes weekends and bank holidays, which doesn't leave much time for the Society to gather the facts and decide if reporting to the regulator is needed.

## 7. Quiz

Ready to test your knowledge? Please complete the quiz below.

Safe use of personal and confidential information are important parts of our roles and responsibilities.

To help us show as an organisation we are compliant, and to ensure that you're aware of data protection requirements in your role, please complete this short quiz.

The required pass level is 80%. Good luck!

**Q1 What is the correct full definition of personal information?**

*(Tick the correct answer)*

Information about a person's health	
Information about a living person who can be individually identified	
Information given to the Society by someone about themselves	
Information about someone's personal life	

**Q2 Which of these items are personal information?**

*(Tick as many as you think are right)*

Video recording of a Zoom meeting	
Number of people taking part in an activity	
An email with an opinion about another person	
Attendance list for a Society activity	
Photo of two people smiling at an Alzheimer's Society event	

**Q3 Which of the following are steps you should take to help protect Society information?**

*(Tick as many as you think are right)*

Anonymise notes you make wherever possible	
Encrypt all information	
Check your email programme hasn't automatically added a wrong email address when you typed an email address into the "To" line	
Keep paper records with personal or confidential data secure and in a locked bag when on the move	

**Q4 Scenario:**

Two family members, Diane and Marc, take it in turns to bring Jean who has a dementia diagnosis, to a Dementia Café each fortnight.

During a session, Diane mentions to a volunteer that she is thinking about moving away and wouldn't be able to come to the group anymore. The volunteer shares this conversation with the Group Coordinator and the rest of the volunteers during the confidential session debrief.

At the next group session a fortnight later, Marc brings Jean to the Café. A different volunteer asks Marc how he's feeling about Diane's move. Marc's shocked to hear about and wonders why the volunteer would say such a thing.

**Question: Who can the first volunteer tell about their conversation with Diane?**

(Tick as many as you think are right)

The Group Coordinator	
Other volunteers at the Café debrief	
Jean	
Any other family member supporting Jean, including Marc	

**Q5 When working at home or at an event, good information security...**

(Tick as many as you think are right)

Is not as important as no-one targets a charity	
Is needed across all Society work activities including video calls, on screen meetings and telephone calls	
Is carefully getting rid of any notes or printed copies by using a proper cross-cut shredder (must be DIN 3 level or above) or waiting until you can take the paper records containing personal data to a Society office	

**Q6 When handling personal or confidential data in your role which of the following help take care of the information:**

(Tick as many as you think are right)

When emailing a group of people who don't know each other, add all email addresses to the 'To' line	
When completing paper attendance registers, scan or copy records onto the Society system as soon as you can and destroy paper securely	
When at home, keep papers/devices out of sight and don't talk about confidential things in front of others.	
When making notes whilst on a call with a service user, note down every detail in a notebook including full names.	
When talking to people about what you do, keep it general so people can't be identified or sound like you are breaking confidentiality.	

**Q7 You've discovered something's gone wrong with data you use. What do you do?**

*(Tick as many as you think are right)*

Investigate to find out all the details before telling your role manager	
Tell your role manager as soon as possible	
Contact the Information Governance team immediately	
Do nothing, as you don't think it was very serious	

**Congratulations – you've now completed the volunteer data protection workbook!**

Thank you for taking time to work through these activities and learn this important information about how to keep personal data safe for people affected by dementia, our employees and other volunteers.

**Next steps**

Let your role manager know you have completed this workbook. They will spend some time talking with you about what you have read and will then update your learning record to show that you have completed this learning.