



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia

Volunteer Data Protection 2024 Workbook

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

1. Introduction

This training is for volunteers who have access to and use personal 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 that we know how to look after personal data when carrying out our roles as it helps us support people affected by dementia.

Even if in your volunteering role you feel like some parts of the module don't apply as much 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, information and advice about handling personal information in your volunteer role.
- Recognise what is personal information and understand why it is important to handle personal information securely in your role and how to do that.
- Know what actions to take if you have concerns over how personal information is being used in any of the activities that you support, including how to identify what might be an incident and who to report it to

Note:

There are notes and exercises you need to complete as you work through the course so make sure you have a pen and paper before you start.

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 one of the foundations of the trusted relationships we have with our service users, supporters, research participants, employees and volunteers alike.

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 \(UK GDPR\)](#) set out what we must do to make sure we 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 the requirements are and how to keep the personal information we hold (and you access, see, hear or use in your role) safe and protected. Making sure that personal information is kept safe and secure at all times - including when it is being collected, transported between locations, stored, shared with others and deleted.

We review every volunteer role to identify if they will be handling people's information and how we can help them to keep it safe and secure - for example having access to certain systems, or a lockable bag for transporting paper records between locations. If you think you might not have everything you need to manage and protect the personal information you may handle in your volunteer role, please discuss 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 attending groups or helping out at fundraising events but, while you may hear some personal information on the day, you are not required to collect, record, share or transport it. In this case, you probably don't need to read the policies. But if your role does involve handling personal data, for example if you email information about service users or record information on service user records, then you should ask your role manager for access to the:

- **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 where information is continually being created by combining pieces of data, often from multiple sources, to make it useful. You may not always realise to what extent organisations are collecting and using information about you.

Sometimes it's obvious what you're sharing and how it might be used and by whom. You also share personal information you may not be 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, more convenient and connected. But you may not always want your information to be shared for the different purposes.

It's your personal information and you should be able to control it.

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.

Think of a piece of personal information about you which you have either shared or may need to share with your role manager for a reason that benefits you.

It could be something which is simply personal, or it could fall into the definition of sensitive information.

Think about how you would feel if:

- this information was left somewhere, or shared with someone who didn't need it, by the person you had entrusted it to? For example, if it was left on a train.
- they used it for a different purpose than they had told you it would be used for, for a purpose that benefits them and not you?
- an organisation you trusted with your information didn't make sure it was kept safe and secure when it was held on their systems, or sent to others who needed it, or being deleted when no longer required?

Activity

Think of a piece of your own personal information that you have either shared or may need to share with your role manager for a reason that benefits you. 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.

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, by the person you had entrusted it to? For example, if it was left on a train 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 purpose other than the one they had told you it would be used for, for a purpose that benefited them and not you?

How would you feel if the organisation who you trusted with your information did not make sure it 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.

So let's have a look at what that means for people affected by dementia...

Information about people affected by dementia

To enable campaigns to raise awareness of dementia and provide the kind of support people want, need and deserve, we need to understand the experiences of people affected by dementia.

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

Let's look at this through the lens of real people

Ananga and Jo have shared her story with the Society. You may hear about a service user's life and experience with dementia in various ways depending upon your volunteer role.

While reading their story think about the following questions and note your answers in the boxes.

What personal information have the people revealed?

What other personal information about Ananga and Jo do you think Alzheimer's Society is likely to hold and where do you think this personal information may be stored?

Ananga & Jo's Vow - 'We'll stand by each other'

Jo: I mean, love is love. It doesn't matter what colour your skin is or how you come across it. Love is love.

Ananga: Well, what can we say?

My name is Ananga, I'm 76... is it? 76 years old.

Jo: Hi, I'm Joanna. I'm the other half.

Ananga: Well, I was born in Dehiwala, in Sri Lanka. I was ten years old when I came to England. I thought that I owed something to this country, and so that's why I joined the RAF.

Both: Pooley Bridge.

Jo: That's where we first met.

Ananga: We were in a cafe. Joanna was sort of staring at me. My eyes just popped open, and I said, 'John, I've just met the girl I want to marry'.

Jo: So we met on the 27th July 1972, and we got married on the 27th July 1974.

Ananga: Two years to the day.

Ananga: Because she wore the sari, she said, 'Well, you'll have to go in uniform'.

Jo: You looked ever so smart and handsome. And I knew we were starting off on an adventure together.

Jo: Your mum taught me how to make curries. Because not many people know Sri Lankan cookery, it's lovely to introduce other people to what we love. So that to us, that's what it means. It means showing of love.

Ananga: I feel fantastic about it, that she's embraced my love for curries.

Jo: Yeah, your culture and things you do.

Jo: It was really rare to see mixed marriage, Asian and white.

Ananga: People gave us six months.

Jo: They couldn't understand that I could fall in love, or he could fall in love, with somebody not of his ethnic origin.

Compare the notes below with the notes you made:

<p>Personal information about people in the video</p>	<ul style="list-style-type: none">• Names• Images and voices• Ananga's place of birth• That Ananga was in the RAF• Ananga and Jo's wedding date
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<p>What other personal information would the Society likely hold about them?</p>	<p>Service user information including:</p> <ul style="list-style-type: none">• Date of birth• Ananga's dementia diagnosis• Ethnicity• Support needs
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As you can see, the Society collects and uses lots of information about many different types of people and each team will use information about people in different ways.

Make sure you know how your local procedures for using people's information in the right way. Now think about your volunteer role...

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 and ability to attract supporters and donors at risk.

It's also a matter of law

We are legally obliged to handle personal information properly.

Failure to comply is 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 be sure you're handling information the right way.

5. How to keep information safe

There are many ways in which the Society applies good information and cyber security protective measures.

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

If you only 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 should not use your own devices (mobile phone, tablet, or laptop) to save any personal 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 the section below you can find advice on the things volunteers need to consider so that you can play your part in keeping people's information safe. These apply to volunteer roles whether you travel to different locations or to an office or are based at home.

Confidentiality

We must take care with how we use, show and talk about information when we are at an external location, an office, at home, and on the move so people who are not entitled to see or hear about it cannot 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 in the first instance consider whether you can anonymise them - for example if you make notes during a call or conversation with a service user, then use the service user's initials.

If they can't be anonymised then make sure they're securely stored while you need to keep them, and securely destroyed. They can be taken to a Society office to 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 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..
- Anonymising information is safer if you can do that.
- The person who the information is about should 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 information to a personal email address, encryption of the email or password protection of attachments should be used. This includes data which may be sent to you from your role manager.

You should also be aware of phishing scams and ensure that you do not click on any links if you are unsure who they came from. If you have any concerns our IT helpdesk can help with this.

In your notes you will have identified ways in which you handle personal information in your volunteer role.

To help you handle information safely remember:

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

S - Stop and Think about whether a recipient needs and is allowed to have information you may be about to share

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

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

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

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

Connect with other volunteers and learn best practice in conversations, at meetings, or at groups.

Being consciously aware is the best step to preventing issues.

Think about the following tips to help you (click each card to flip it and find out how to avoid the things stated):

Protect paper records in transit.

If you have to carry paper records between locations, such as an attendance list from a group back home or to an office where you will be scanning or typing them onto the Society's systems, make sure you use a lockable bag. If using public transport keep the bag with you at all times and if you are traveling by car, store the bag out of sight (in the boot for example) and do not leave the car unattended unless in an emergency.

Check outlook has auto populated the right person/email address.

Outlook has the time-saving ability that it will complete an email address you start to type in. This is great, so long as you check Outlook is suggesting the right person! Double check the right people have been selected and delete from the auto-populate list any email addresses you won't contact again. Or if you think this is a large risk for you, turn off this functionality.

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

Before sending personal information to another organisation or person outside the Society, especially if the information is particularly sensitive or is about multiple people, check the classification of the information using the Handling Information Guidelines you can get from your role manager and make sure the right level of security is used. For example, when sending service user details to a local authority always make sure it is sent encrypted using an approved method. The guidelines have been updated on how to send emails securely, so please make sure you read them to help you choose the best method.

Use BCC if people don't know each other or each other's email addresses.

If you are emailing lots of people who don't know each other and don't need to know the identity of other people who are receiving the email, use the blind carbon copy (bcc) function. Before sending an email, always review the 'to'/'cc'/'bcc' fields and make sure you have selected the right recipients in the right fields.

Don't tell other people personal information about someone.

For example, if you make calls to people (such as service users or supporters) in your volunteering role, don't leave voicemail messages that give details of what you are calling about as someone else may hear / pick up the message who isn't entitled to know that information.

Only make factual notes - not opinions

People have a right to information that we hold on them, this includes anything that has been written down about them. Make sure that any notes made on our systems or in emails only give factual information e.g., facilitators emailing updates to staff, Companion Call volunteers making notes of a call, or group volunteers making notes to share at a debriefing session.

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...

Time is of the essence when people's information has not been kept safe!

Act quickly

If you identify that an incident relating to data protection has occurred, you must inform 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 to data protection breaches which may cause harm to the people whose data is involved to the Information Commissioner's office, so it is essential that you act quickly.

The 72-hour timescale includes weekends and bank holidays, which doesn't leave much time for the Society to gather the facts and make a decision on whether reporting to the regulator is required.

7. Quiz

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

Data protection and handling personal information is an important part of our roles and responsibilities.

To make sure that as an organisation we are compliant, and to ensure that you are fully 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 definition of personal information?

(Tick the correct answer)

<input type="checkbox"/> Information about a person with dementia	
<input type="checkbox"/> Information which can be used to identify a person	
<input type="checkbox"/> Information about someone's personal life	
<input type="checkbox"/> Information given to the Society by someone about themselves	

Q2 Which of these items is personal information?

(Choose as many as you think are right)

<input type="checkbox"/> Number of people participating in a research activity	
<input type="checkbox"/> Photo of two participants crossing the finish line of a Memory Walk	
<input type="checkbox"/> Attendance list for a Singing for the Brain session	
<input type="checkbox"/> Opinion about another volunteer stated in an email	
<input type="checkbox"/> Voice recordings of participants of service user groups on Zoom	

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

(Choose as many as you think are right)

<input type="checkbox"/> Encrypt all information being sent externally by email	
<input type="checkbox"/> Keeping paper records containing personal data locked up when on the move with it	
<input type="checkbox"/> Check that Outlook has not auto-populated the wrong person's email address	
<input type="checkbox"/> Encrypt or password protect emails sent externally which contain personal or sensitive information	

Q4 Match the activities below with the protective measure you can take:

(Draw a line from the item on the left to the correct option on the right)

Working in non-office locations/at home	Speak in general terms about your activities, without naming people you meet / help
Talking to others about your volunteer role	Scan or copy records onto the Society system as soon as you can and destroy paper securely
Emailing a group of people	Don't talk about confidential things in front of others, keep papers/devices out of sight
Completing paper attendance registers	Remember to use the bcc function if you need to email multiple people

Q5 You've discovered there has been a data protection incident. What do you do?

(Tick the correct answer)

<input type="checkbox"/> Inform your role manager as soon as possible	
<input type="checkbox"/> Do nothing, as you don't think it was very serious	
<input type="checkbox"/> Investigate to find out all the details, before informing your role manager so you can share all of the facts	
<input type="checkbox"/> Inform the Information Governance team immediately	

Q6 Practicing good information security when working home...

(Choose as many as you think are right)

<input type="checkbox"/> Means anonymising personal information when you can, using a DIN 3 level cross-cut shredder (if your role requires you to have one) or waiting until you can take the paper records containing personal data to a Society office	
<input type="checkbox"/> Means that we must consider what information is handled in shared spaces at home and plan carefully to keep information confidential	
<input type="checkbox"/> Means only creating records containing personal information if your volunteer role requires you to do so	
<input type="checkbox"/> Is not as important as when you are working in the office	
<input type="checkbox"/> Is required across all Society work activities including video calls, on screen meetings and telephone calls	

Q7 Scenario:

Two sisters take it in turns to bring their mother, who has Alzheimer's disease, to a Dementia Café each fortnight.

The first sister, Diane, mentions to a volunteer that they are going to "start having some difficult conversations about putting Mum in a home". The volunteer shares this with the Group Coordinator and the rest of the volunteers during the session debrief.

At the next group session a fortnight later, the other sister, Janet, brings her mum. During a conversation, a different volunteer says to her "How are you feeling? I understand you're thinking of a care home for your mum". Janet is shocked to hear this and wonders why the volunteer would say such a thing.

Question:

Who can the volunteer tell about her conversation with Diane?

(Choose as many as you think are right)

<input type="checkbox"/>	• The Group Coordinator
<input type="checkbox"/>	• Other volunteers at the Café debrief
<input type="checkbox"/>	• Janet
<input type="checkbox"/>	• Any other family member

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.