

CONFIDENTIALITY FACTSHEET

Q What is confidentiality and why is it important?

A Confidentiality is defined as 'the state of keeping or being kept secret or private'. Confidentiality is one of the key principles underpinning the relationship between the Trust and its beneficiaries.

What this means is that you can be certain that the staff within the Trust respect your privacy, understand and comply with the law and will not tell people outside the Trust personal things about you, without your consent. This is important for your peace of mind and for giving you confidence that you can talk to us.

Q What type of confidential information does the Trust record?

A As a beneficiary, we want to make sure that we have the correct information to enable us to communicate with you and advise and/or support you appropriately.

We keep the information we collect up to date, accurate and relevant. The kind of data we collect includes the following examples:-

Personal details

- Full name and address
- Date of birth
- Telephone numbers (landline and mobile)
- E-mail address
- Details of Third party contacts – e.g. your partner, carer or advocate.

Financial information

- Bank account details (so we can pay your Annual General and Health Grant)
- The amount of your annual grants and the balance on your Trust accounts
- Details of any Major Advances and Emergency Advances.

Health and wellbeing information

- Details of your original Thalidomide damage
- Any health problems and medical information you have told us about
- Records of your enrolment in research studies or responses to questionnaires
- Details of any aids and adaptations you use.

Q Who sees my confidential information?

A The information held on individual beneficiaries is only seen by Trust staff. All staff have access to your information as this allows the team to work together to support you and meet your needs. It also saves you the bother of having to explain things repeatedly, to different people, when you call us.

Confidential information about individual beneficiaries is not shared with the NAC (although NAC members also sign a confidentiality agreement) and NAC members are not party to any discussions in Trust meetings where personal identifiable information is shared.

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Q How can I be assured that that Trust staff will keep my information confidential?

A All staff working for the Trust have been fully trained about confidentiality. They have also signed an agreement as part of their contract of employment stating that they will adhere to the Trust's *Data Protection Policy* and treat all sensitive information on individual beneficiaries confidentially.

Q How will my information be stored?

A Individual beneficiary information is recorded on a secure computer system. Where paper records are made, these are filed securely in an individual beneficiary file in a locked cabinet. Only Trust staff have access to each beneficiary's records.

Q Will my confidential information be disclosed to anyone else?

A In almost all circumstances your personal, identifiable information will not be disclosed to anyone outside the Trust without your full, informed consent.

Where information needs to be shared; for example where we need to write to your GP on a specific health issue; we will ask for your consent first, by letter or e-mail. We will show you a copy of any letter before we send it. And if for some reason we are unable to share the letter with you we will inform you and explain why.

If you have been referred to one of the Trust's beneficiary volunteers for support or agree to have a Holistic Needs Assessment done by a volunteer, they will have access to some personal information - such as your address and telephone number - with your consent. If you choose to share other confidential information with them, this will only be disclosed to Trust staff with your consent and will not be shared with anyone else.

Q Are there any circumstances in which information would be disclosed?

A There are some circumstances where we would disclose your personal information with others. If the Trust staff thought you, or another person, were at serious risk of harm, we would have a duty under our *Safeguarding Policy* to inform the relevant authorities. Where possible we would let you know before sharing your information.

Q What if there is something I don't want widely known?

A All the Trust team are non-judgemental professionals, with a high regard for each beneficiary's wish for privacy. However if you are concerned about a specific piece of personal information that you feel should not be shared with the whole staff team, please let us know and one of the Management team (Deborah, Katy or Jenny) will talk to you about what we can do to restrict access to that information.

Q What happens if I feel my confidentiality has been breached?

A A breach of confidentiality can be very upsetting. It can weaken the relationship between you as a beneficiary and the Trust. If you feel this has happened, the Trust will investigate fully and take appropriate action in accordance with our *Data Protection policy*.

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Q Can I ask to see my personal information?

A Under the Data Protection Act 1998 you have the right to ask to see the information we hold on you. To do so, you will need to contact the Trust, either by telephone 01480 474074 or e-mail hello@thalidomidetrust.org and ask for a 'Subject Access Request' form. You will need to tell us what information you want to see and return this to the Trust office, where your request will be considered by the Director. Due to the sensitive nature of the information, we would generally expect beneficiaries to come to the Trust office to view the information.

Q What if there is something I don't want widely known?

A You can download a copy of our *Data Protection policy* from the Trust website or request a copy by phone 01480 4747074 or email hello@thalidomidetrust.org

If you would like to discuss a specific confidentiality issue, you can call one of the management Team (Deborah, Jenny or Katy) on 01480 474074.