

Appendix 7 Your rights over your information

1. Request for access

Your request must be in writing and be signed and dated. You must provide proof of your identity.

Following a request, release of information is only done in consultation with a Senior Staff member. Care must be taken not to include third party correspondence or references.

We aim to respond as soon as possible to such a request and, in any event, ensure we give you your information within a month of receiving your application.

With your agreement, your information will be given to you either as a paper copy posted to you tracked and signed, or as a word document with screen shots of database 'pages'. This is as 'portable' as we are able to make it for you.

2. Request to amend or correct information

If your request is to change contact details or unsubscribe from mailings, we will process this before the next contact or mailing is due.

If your request is to amend information, we will respond within a reasonable timeframe. If we were concerned that this could mean that someone would be a danger to themselves or others or we believed a child or adult is at risk of harm, we may not be able to make the requested change. We would discuss this with you.

3. Request to restrict who has access to your information

Please be assured, we will not share or distribute your personal information to third parties, including any contact details you have given us, unless we: have your permission; or are required to do so by law; or are concerned that this could mean that someone would be a danger to themselves or others; or we believed a child or adult is at risk of harm.

In the same way, unless any of these circumstances occur, we will always follow any other restrictions you wish us to follow about who, outside our organisation, has access to information.

Due to the structure of our database, all staff potentially have access to your information and it is very difficult to restrict access. However, staff sign a confidentiality agreement and only access information on a 'need to know and use it' basis.

4. Request to delete your information

If you make this request, we follow this practice:

The Information Commissioner's Office recognizes that deleting information from a system is not always a straightforward matter and that it is possible to put information 'beyond use' provided the data controller:

- Is not able, or will not attempt, to use the personal data to inform any decision in respect of any individual or in a manner that affect the individual in any way;
- Does not give any other organisation access to the personal data;
- Surrounds the personal data with appropriate technical and organisational security; and
- Commits to permanent deletion of the information if, or when, this becomes possible.

We will therefore, as a first step, make your information record **inactive** or 'beyond use' until such time as we are confident that there would be no unforeseen negative consequence of any full deletion process.

5. Right to Object to processing

Please be assured, we will not share or distribute your personal information to third parties, including any contact details you have given us, unless we: have your permission; or are required to do so by law; or are concerned that this could mean that someone would be a danger to themselves or others; or we believed a child or adult is at risk of harm.

However, you have the right to object to your data being processed. This may include receiving marketing or your data being (anonymously) used for statistical research. If you do object to your data being processed for such activities or any other activity outside of those stated in the above paragraphs then processing will stop immediately.

Please note that we are required by law to keep a record of donations. For more information please see **Appendix 6**



Help for today • Hope for tomorrow

Spinal Muscular Atrophy (SMA) is a neuromuscular condition

We support and empower anyone affected by SMA. We are advocates for better services and access to new treatments, raise awareness and help fund and facilitate research related initiatives.