

## Confidentiality Policy and Procedure

### ***Introduction***

The aim of this policy is to provide a set of guidelines for staff, trustees and volunteers.

Confidentiality is a fundamental principle of the Niemann-Pick Disease Group (UK), hereafter known as NPDG (UK). This guidance is designed to help staff, trustees and volunteers apply the principle in a range of different circumstances. It cannot cover every possible situation and staff should contact the Chair of the Board of Trustees with any queries.

### ***The principle of confidentiality***

NPDG (UK) provides a confidential service to clients, who are defined as: families, carers, parents, professionals, or persons affected by or connected to NPD.

**Nothing learned during the course of dealing with a client (including the fact that an enquiry has been made) will be passed to anyone outside NPDG (UK) without the client's express permission.**

The client may be a parent or a child or young person. The principles of confidentiality apply to children and young people who are clients as well as to parents.

Where clients are seen face to face:

- Interviews are held in visual and aural privacy
- Clients are not required to state the nature of their enquiry in front of others
- Referrals are made only with the knowledge and consent of the client.

If a client agrees to information being given to a third party, there is no breach of confidentiality. However, there are circumstances in which a **breach of confidentiality** may be authorised.

Where clients are dealt with over the telephone:

- Staff should ask clients whether, when returning a call, it is acceptable to leave a message on an answerphone or with a third party.

### ***Protecting confidentiality***

Everyone working or volunteering for NPDG (UK) is expected to have an understanding of the confidentiality policy and its importance. This includes all management and administrative staff, Trustee Board members and anyone else offering services as part of the NPDG (UK).

All staff need to have a practical understanding of what it means for the operation of the organisation. This ranges from the most practical day-to-day matters such as ensuring staff don't discuss cases where they can be overheard by anyone to considering the impact of the principle on potential new services.

However some element of discretion has to be used.

### ***Policy work***

Client's names or any material that could lead to their identification should not be included in any NPDG (UK) policy work. For example, if a copy of a letter was sent out to illustrate a problem any name or identifying reference number should be obscured from the copy. Clients will not be identified without their express permission.

### ***Photos and media work***

Client's photographs will only be used if they have filled in and signed a permission form. We will seek to avoid the exploitation of parents and children and will offer appropriate advice on handling media enquiries. Members, families etc. will never be pressured into acting as media contacts and will always be given the opportunity to decline a particular interview.

### ***Breaching confidentiality***

Confidentiality may be breached only where, based on evidence:

- someone is in danger
- the good name or reputation of the NPDG (UK) is at risk
- disclosure of information is required by law
- a potential conflict of interest exists.

A decision to breach confidentiality should always be taken very seriously. The general rule is that confidentiality should not be breached without authorisation from the Chair of the Board of Trustees.

Before a breach of confidentiality is sanctioned a judgement as to whether there is a serious risk of danger to the patients/family or others or to the NPDG (UK) needs to be made. This decision will be based on:

- the balance of probability that such a risk exists
- the likelihood of the risk materializing
- the impact of the risk should it materialize.

A breach of confidentiality will not be sanctioned where there is little prospect of the risk becoming reality or where there is no evidence that there is a risk.

However some situations require an immediate response, e.g. where safety is the overriding consideration in which case it may not be possible to locate a member of the Chair of the Board of Trustees.

### ***Immediate risk***

It is for staff to determine whether there is an immediate risk to the safety of someone and to decide on the best course of action to take without consulting the Chair of the Board of Trustees.

### ***Safety of an adult***

Staff may be concerned for the safety of a client. For example a client may have expressed a wish to end their own life. In such circumstances, the client should be encouraged to seek appropriate help and support and offered assistance to obtain this help if necessary. However, unless the client gives permission, the NPDG (UK) would not breach confidentiality in these cases.

### ***Risk to the reputation of the NPDG (UK)***

Though rare, there can be instances where information relating to a client needs to be released to protect the good name or reputation of the NPDG (UK). Such a decision should always be made in consultation with Chair of the Board of Trustees.

### ***Conflict of interest and clients***

In some situations client confidentiality can be breached in so far as a client has to be told that the other party to a dispute has already consulted the NPDG (UK). For detailed guidance see the NPDG (UK) Conflict of interest policy.

### ***Third parties - Giving information to third parties***

Confidentiality is not breached if the client agrees to information being given to a third party. For example if a NPDG (UK) staff member attends a meeting on behalf of a parent it may be necessary to make participation conditional on all agencies understanding that the NPDG (UK) is representing the client and will report back to her/him.

### ***Enquiries on behalf of a third party***

If someone approaches the NPDG (UK) with an enquiry on behalf of someone else, you can provide information and initial advice and send leaflets to the enquirer to be passed on. You should not send material direct to the third party, as you have no way of knowing that it is appropriate or desired.

The NPDG (UK) may act on behalf of the third party only where the enquirer has been formally appointed as the third party's representative by way of:

- a power of attorney
- a court order
- her/his status as the formal personal representative following the death of a client (either through the will or following appointment as administrator).

Evidence of the appointment should be produced and a copy retained on file.

### ***Death of client***

Death does not end the NPDG (UK) duty of confidentiality to the client. If a client has died, information relating to any records held should be given only to someone who is the dead person's executor or personal representative. Evidence of this status must be retained on file if information is released.

If the police make a formal request for information following the death of a client, e.g. where there are suspicious circumstances, the consent of the executor or personal representative should be sought to release records.

### ***Trustee Boards***

The Trustees should not have routine access to client records.

However, in certain situations, Trustees will need to see client records. For example, in certain cases of complaints, the Chair or another member of the Board will need the case records.

As Trustees are responsible for the overall management of the Charity it is important that they be encouraged to play an active role. However, sensitivity is needed about potential contact with clients. It can be helpful for a Trustee to sit in on a parent's group meeting. This should be with the express permission of the clients.

### ***Break-ins and theft***

If confidential records are stolen in a break-in or in any other way, the theft must be reported to the Chair of the Board of Trustees and the police. The report to the police must stress the confidential nature of the records and the importance of them being returned unread if they are found.

Client details should not be disclosed to the police. Where case records have not been stolen, but an intruder might have examined them, a report should be made to the Chair of the Board of Trustees.

### ***Contacting clients***

The way(s) in which clients may be contacted should be ascertained at the time of the initial contact and noted on the client record. It should also be checked whether there is a problem leaving messages with third parties who may share the accommodation, or on answer machines. Care should be taken when contacting clients in case confidentiality is inadvertently breached. E-mail enquiries should be handled securely.

A common sense approach should be used. If the client has e mailed or written to us with an enquiry and given their telephone number, we can imply consent to call them and leave a message, unless they have explicitly asked us not to leave a message.

### ***Case records***

#### ***Storage of records***

Clients' case records and other notes taken must be kept securely. Correspondence and other records must be kept in discreetly and anonymously labelled filing cabinets.

The storage of data is covered by the Data Protection Act, which means you should not keep unnecessarily detailed records, particularly of personal information such as religion, sexuality, unless it is essential to know this information to provide advice or appropriate services.

Records containing any advice given should be stored for a period of at least 6 years and in the case of complaints, 16 years, as this is the latest period to start an action for negligence. Other records may be disposed of securely at the workers discretion. Records which identify individuals must be shredded.

When using a computer, data must be stored securely, by the use of a password. Where details are kept on disk these should be stored securely.

The National Development Manager (NDM) of the NPDG (UK) is the Data Protection Officer for the organisation and is responsible for regular revision of data protection implications.

#### ***Taking client records from the office***

Case records and case notes may be removed for the purpose of home visits, tribunal/court representations, outreach work and any other exceptional circumstance on the authorisation of the NDM. Every care should be taken to ensure they are not left unattended, are secure and returned to the office as soon as possible.

### ***Lost records***

If confidential records are lost, this should be reported to Chair of the Board of Trustees and the police. The report to the police must stress the confidential nature of the records and the importance of them being returned unread if they are found.

### ***Client access to case records***

Clients have the right to see their own case records and letters written or received on their behalf. Copies may be given to clients, but the originals should be retained in the office files. Exceptions may be made where the information held may be damaging to the client's wellbeing (e.g. a doctor's letter which states that the client is terminally ill) or where a third party is identified (e.g. a note of a telephone call with the client's sister, in which abuse is alleged).

Where a client has made a complaint or a claim involving liability for wrong advice against the NPDG (UK), any records or correspondence relating to the claim or complaint are confidential to us and should be stored separately to the original case record.

### ***Third party access to case records***

A third party can have access to client records only with the client's express permission preferably in writing. This permission, and details of which documents were supplied to whom and why, must be kept on the case record. Exceptions include our insurers and solicitors.

### ***Witness summons***

If a worker receives a summons, s/he should contact the Chair of the Board of Trustees.

Whether a NPDG (UK) worker can be forced to give information in court relating to a client is a matter for debate. Solicitors and qualified legal advisers are protected by legal professional privilege and cannot be required to divulge confidential information obtained in the process of giving legal advice.

Following receipt of a witness summons, application may be made to the magistrate's court in person, or to the Crown or High Court in writing, to explain that the information has been obtained in the course of a confidential interview and to ask whether the evidence is still required. If the judge or magistrate rules that the evidence must be given, any refusal to go to court will be seen as contempt. Failure to attend may result in a warrant being issued and eventual arrest.

The client should be informed if a worker receives a summons and the procedures and penalties explained to her/him. It must be made clear that attendance and disclosure of information may be required by the court even if the client objects. In no circumstances should the evidence to be given be discussed with the client.

## **Crime and the police**

### ***Disclosure of crimes***

It is an offence to assist in the commission of a crime. Being aware that a crime might take place is not, except in very unusual circumstances, assisting in the commission of that crime. However, if during the course of a meeting a client begins to give information about criminal activities, it is good practice to warn the client of the consequences as the adviser could be summoned as a witness.

There are two exceptions where there is a legal duty on advisers to report information:

- terrorism
- drugs and money laundering.

In Northern Ireland, it is a duty under the Criminal Law Act 1967 to disclose information about a criminal offence.

#### ***Police visits and requests for information***

There is no legal duty for staff to give information to the police. Police Officer(s) visiting the NPDG (UK) asking for information about clients should not be allowed into any room where confidential records are kept thus avoiding advantage being taken of the rights conferred by PACE.

(Section 19 (3) of the Police and Criminal Evidence Act 1984 (PACE) (in N Ireland, Article 21 of the Police & Criminal Evidence (NI) order 1989) gives general powers to police officers, lawfully in any premises, to seize anything that they reasonably believe is evidence in relation to an offence under investigation, which might otherwise be concealed, lost, altered or destroyed. Preventing access to a room where records are kept forestalls the use of these powers.)

No questions about clients should be answered. The police officer(s) should be told about the confidentiality policy as an explanation for not answering questions. If the police persist in their enquiries, further guidance should be sought through the Chair of the Board of Trustees.

The client's permission to give the police information may be sought. However if the police do not permit the client to be approached in this way or if the client refuses, a witness summons or subpoena will be required before information can be released.

#### ***Excluded material***

The police may apply to a magistrates' court for a search warrant to inspect documents. Such a warrant would not however extend to excluded material.

"Excluded material" includes documents covered by legal privilege. It is possible that legal privilege applies to client case records and therefore confidential papers such as case notes and files are not open to such inspection.

If the NPDG (UK) is visited by police with a search warrant, contact the Chair of the Board of Trustees for advice.

#### ***Production order***

In certain situations, the police are able to obtain a production order. In the event that such an order is produced, the Chair of the Board of Trustees should be notified and will seek specialist legal advice.

#### ***Terrorism***

Under the Terrorism Act 2000, it is an offence for a person holding information about acts of terrorism to fail without reasonable excuse to disclose that information.

The Act applies to individual workers rather than to the NPDG (UK) as an organisation. However, it is a defence for employees to prove that they disclosed matters in accordance with procedures laid down by their employers. Therefore, if workers believe or suspect they have information about terrorism, they must consult the Chair of the Board of Trustees.

### ***Drugs and money laundering***

The Drug Trafficking Act 1994 makes it a criminal offence to fail to report to the police suspicion or knowledge of drug money laundering gained during the course of contact with a client. You will normally be required to disclose information. If you know of, or suspect, such activity inform the Chair of the Board of Trustees.

### ***Social security fraud***

The Social Security Administration (Fraud) Act 1997 created two criminal offences concerning benefits. These are the offences of making or assisting with fraudulent claims and failing to notify changes of circumstances concerning benefits.

You should therefore do nothing to help facilitate a misrepresentation or failure to notify a change in circumstances i.e. you should not help to fill in a claim form or a review form which you know is inaccurate.

### ***Powers of social security inspectors***

Social security legislation, including the Child Support Acts, gives wide powers to inspectors to make enquiries and to examine records. These powers in theory extend to the examination of our client records.

In fact these powers have never yet been used in this way in social security investigations and the Child Support Agency confirms that there is no intention to do so in their investigation procedures.

In the event that an inspector asks for access to case records, you should check the inspector's identification and contact the Chair of the Board of Trustees for advice before allowing access.

### ***Staff and other personnel records***

Staff and other personnel records (e.g. volunteer expenses) should be kept in a secure location, preferably in a lockable filing cabinet or cupboard.

Staff who have access to personal information about another member of staff should not pass this on, unless there is a risk to the NPDG (UK) or reputation, or there is a breach of other procedures e.g. health and safety, if it is not disclosed.

Staff are encouraged to report concerns about a colleague's work where they believe that there is a risk to the NPDG (UK) services or reputation and will be supported in so doing.

Staff have access to their own personnel files.