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GOOD PRACTICE GUIDE

# Carers and confidentiality



## **Our aim**

We aim to ensure that care, treatment and support are lawful and respect the rights and promote the welfare of individuals with mental illness, learning disability and related conditions. We do this by empowering individuals and their carers and influencing and challenging service providers and policy makers.

## **Why we do this**

Individuals may be vulnerable because they are less able at times to safeguard their own interests. They can have restrictions placed on them in order to receive care and treatment. When this happens, we make sure it is legal and ethical.

## **Who we are**

We are an independent organisation set up by Parliament with a range of duties under mental health and incapacity law. We draw on our experience as health and social care staff, service users and carers.

## **Our values**

We believe individuals with mental illness, learning disability and related conditions should be treated with the same respect for their equality and human rights as all other citizens. They have the right to:

- be treated with dignity and respect
- ethical and lawful treatment and to live free from abuse, neglect or discrimination
- care and treatment that best suit their needs
- recovery from mental illness
- lead as fulfilling a life as possible

## **What we do**

Much of our work is at the complex interface between the individual's rights, the law and ethics and the care the person is receiving. We work across the continuum of health and social care.

- We find out whether individual care and treatment is in line with the law and good practice
- We challenge service providers to deliver best practice in mental health and learning disability care
- We follow up on individual cases where we have concerns and may investigate further
- We provide information, advice and guidance to individuals, carers and service providers
- We have a strong and influential voice in service policy and development
- We promote best practice in applying mental health and incapacity law to individuals' care and treatment

## INTRODUCTION

### About this guide:

This is a guide for carers and professionals about information sharing and confidentiality in mental health.

### Carers

We hope to help you to understand more clearly what you can expect from professionals looking after the person you care for. We aim to explain what the duty of confidentiality means for professionals and how you can quite reasonably look to them to work with you so that you have the information you need to care for your relative, partner or friend.

*Carers: we use the term here to refer to those who provide ongoing help and support, to a relative, partner or friend.*

### Professionals

We aim to provide updated guidance on how to balance sometimes conflicting duties of confidentiality and of effective communication, remaining focussed at all times on your patient's best interests.

This guide is about protecting individuals' confidentiality, while sharing and seeking necessary and appropriate information. It is not, and is not intended to be, a comprehensive guide for professionals and carers on how to work together.

We cover:

- Confidentiality
- Capacity
- The need for consent from the individual
- Information sharing when the individual does not consent, or is not capable of consenting
- Some particular issues for parent-carers
- People aged under 18
- Named persons

*This document uses the term individual to mean people with mental illness, learning disability and related conditions. We have used fictitious names in case scenarios.*

### Common scenario:

*Mrs D phoned the Commission. She was very distressed about the care of her 22-year-old son, John, who had been admitted to hospital for the second time with what was clearly a psychotic illness. The first admission was voluntary; this one was under a compulsory order. She had a very difficult time trying to look after him after the first admission. He became very negative about her. He was using illegal drugs and alcohol, which she thought made him worse. She had been trying to get an appointment to speak to his consultant, to get information about his current illness and treatment. However, she had been told that this was impossible, for reasons of confidentiality, because her son was unwilling to consent to such discussion.*

Everyone staffing the Commission's telephone advice line has received phone calls like Mrs D's. These calls are often from parents who are distressed about the level of care their son or daughter is receiving now they have reached adulthood. Sometimes they believe that the treatment is not enough, or the wrong kind of treatment. Generally, they feel that their views are not being listened to properly and that their son or daughter's care is suffering as a result.

It is not only parents who call us – partners, children, siblings and friends also contact us with similar concerns. By the time they get in touch with us, relatives and carers may have become very frustrated trying to get information and having their views heard. Sometimes, the family and the service have developed extremely polarised views, and sometimes their relationship has become very difficult.

## **Confidentiality**

### **What does the 'duty of confidentiality' mean?**

When any one of us talks with a doctor, nurse or other health professional in a private consultation, we expect that what we say will stay private. This principle is central to trust between patients and their doctor or other health professional.

All health professionals are bound by law and professional codes of conduct to this duty of confidentiality to their patients. If they breach confidentiality they could face disciplinary measures or legal proceedings, including being sued, dismissed or losing their licence to practice.

### **What is the guidance on confidentiality?**

Of the professional regulatory bodies, the General Medical Council (GMC) gives the most detailed guidance on confidentiality and is referred to in this guide. However, other regulatory and professional bodies, such as The Nursing and Midwifery Council (NMC) and the British Association of Social Workers, have similar general guidance on confidentiality.

### **The Law:**

- *The Age of Legal Capacity Act (Scotland) 1991* is relevant when the patient is a young person or child.
- *The Data Protection Act 1998* sets out statutory duties for services in how they record, store and disclose sensitive personal information, and professionals will be in serious breach of contract of employment and of their professional duty if they break these. This law also sets out the rules for individuals to access their own medical records, and the particular circumstances in which it may be possible, legally, for a carer to do so.
- *Article 8 of the European Convention of Human Rights (ECHR), right to privacy*
- The principles in *the Mental Health (Care and Treatment) (Scotland) Act 2003* clearly state the importance of:
  - Giving carers the information they need to help them care for the person
  - Listening to carers' views about how the Act is applied to the person's care
  - Taking the carers' needs and circumstances into account.
- *The Adults with Incapacity (Scotland) 2000 Act (AWI) SI(4)(b)* states that, in determining if an intervention is to be made, account should be taken of:
  - The views of the nearest relative and the primary care of the adult in as far as it is reasonable and practicable to do so.

So, while mental health professionals generally understand the value of carer involvement, they may find it difficult in their day-to-day work to balance managing to involve carers on one hand, while maintaining their common-law and professional duty of confidentiality to their patient.

### **The General Medical Council guidance says:**

"Patients have a right to expect that information about them will be held in confidence by their doctors. Confidentiality is central to trust between doctors and patients."

The guidance is clear that this duty of confidentiality is central but not absolute.

Broadly their guidance covers the sharing of information when:

- An individual gives express consent to the disclosure or where disclosure can be justified in the public interest, usually where it is essential to protect the patient or someone else from risk of death or serious harm.
- They give further guidance on considerations when the patient lacks capacity, or has fluctuating capacity (this is about whether the individual understands the matter well enough to be able to make a decision).
- Specific guidance is also given about patients aged 0-18.

## Do carers have a duty of confidentiality?

Unless a carer is providing care under a contract, or the individual has made his or her views on confidentiality of information known to the carer, there is no express requirement that a carer must respect the individual's confidentiality. Nevertheless it may be implied from the circumstances that the person does not want information about him or her to be disclosed by the carer. The carer would have a duty to respect confidentiality (express or implied) unless sharing of information is in the public interest. If carers have obtained confidential information about an individual, we think that they should make every effort to respect the person's right to privacy.

## Listening to carers

Provided a carer already knows that a person is using mental health or learning disability services, there can be no breach of confidentiality in seeing the carers and listening to what they have to say. This need not, and should not, involve the sharing of confidential information without prior consent.

### GMC 'Confidentiality' s66 says

*"You should not refuse to listen to a patient's partner, carers or others on the basis of confidentiality. Their views or the information they provide might be helpful in your care of the patient. ..."*

**It is rarely acceptable for practitioners to refuse to see carers, simply because the individual has not given consent.** Indeed, getting information from, and about, family or carers is essential for a comprehensive assessment of a person's mental health and social circumstances.

If a practitioner meets carers on a listening basis, everyone involved should be clear about what this is about, including the individual. Again, the individual may be reassured by being present at such a meeting. However, this has to be balanced against the possible risks to his or her relationship with the carers. It can be helpful to discuss the best way to respond to emotional distress, unusual behaviour or psychiatric symptoms and also the likely course and treatment of particular mental illness.

It may in some situations be helpful to identify a specific practitioner to take on this responsibility, perhaps one who has minimal or no direct contact with the patient.

Even when a practitioner is unable to give personal information about the individual, he or she can support the carers by giving general information about mental illness or learning disability. Carers may also welcome information about local and national support groups.

*When recording information gained from carers or a third party, this should be clearly identified as such. If possible, such information should be recorded in a separate section of the records as this information will be exempt from personal information requests.*

## **A carer asks a person's doctor, social worker or nurse, for information.**

### **What should happen?**

- The first point for the professional to consider is that the carer may not know about confidentiality issues, and certainly may not realise that the question they are asking raises any confidentiality issues. So the first step is to explain that this is something the professionals do have to take account of, and that they will have to check out the views of the individual in question before they can give any answer or information that might breach confidentiality.
- The next step is for the practitioner to assess the person's capacity to give or withhold consent to the sharing of information. Assessment of his or her capacity should focus on the particular decision about sharing personal medical information. A person may have capacity to make some types of welfare decisions, but not understand, or be able to weigh up, the implications of consenting to sharing of personal information. Bear in mind the need to establish whether the individual understands the value of sharing information as well as the risks of **not** sharing certain information with a carer.
- Simple agreement to sharing information – or not refusing – should not be taken as informed consent. The assessment of the person's capacity may be difficult and may require a second clinical opinion or consultation with the multidisciplinary care team. It becomes more difficult when, as is sometimes the case, the person's capacity fluctuates over time, or when what the person says about sharing information is different from what they actually do. For example, he may say: "I don't want you to talk to my mother about me or my treatment", but will phone his mother from the ward, unhappy about his treatment and asking for her help. In such situations staff may need to directly address these inconsistencies with the individual.

### **WHEN AN INDIVIDUAL HAS THE CAPACITY TO CONSENT TO THE SHARING OF INFORMATION:**

If an individual has the capacity to consent to the sharing of personal information, anyone working with them should ensure that they understand the benefits of sharing, and indeed the possible consequences of not sharing, information.

#### ***If they agree to share information:***

*"John has the capacity to give informed consent and he agrees to the sharing of information. This information can then be shared to the extent that John agreed."*

- The practitioner should discuss with John who the information can be shared with and the nature of the information to be shared. They should also be mindful of any potential benefits and possible drawbacks to sharing information that John may not have considered.
- John may benefit from the support of an advocacy worker.
- The practitioner should make a record of the discussion with John and, if possible, get his written consent to share information.
- An agreement to share information does not confer a general right of access to John's records, or to non-relevant information.
- John's agreement to sharing information should be kept under review.



### ***If they don't agree to share information:***

*"Jean has capacity and says she does not want information shared. The practitioner is, in this case, generally not in the position to be able to disclose information."*

It is understandable that Jean may be worried about the prospect of other people being given personal and private information about her and may refuse a general request to disclose information. However, the carer may be an important support for her, and may also be able to provide an important alternative view of how well she is coping, if this is something that has been an area of difficulty in the past.

We emphasise that it is rarely acceptable for practitioners to refuse to talk to carers simply because the individual has refused to give blanket consent for them to do so. *If the practitioner says to Jean "your mother wants to see me to talk about your illness", Jean may well reply "I don't want you to talk to my mother."*

This should not generally be the end of the story.

- The practitioner should explore with Jean her reasons for not wanting information to be disclosed. They should try to work with her to select and negotiate information that could be shared.
- The practitioner should also plan to come back to the issue in the future, so that obtaining consent to a helpful level of information sharing becomes part of an ongoing discussion with Jean.
- If the carer is involved in any way in ensuring that Jean is safe and well at home, they really need to be given adequate information about when she will be at home, for example, on discharge or overnight leave from hospital, and also if there are any particular changes they need to be aware of or seeking help about.
- If the carer is involved in the support plan when Jean is on leave it is important to gain information from them about how the time on leave has been.

[The MWC report into the care and treatment of Mr N illustrates this point]:<sup>1</sup>

*There may be some situations where there are public or personal safety concerns which make information sharing without consent necessary. This is discussed later in this document.*

### ***If they agree to share some information:***

*"Sue is happy for her carer to be told factual details about her diagnosis and its effects, but not to be given information about her relationships or alcohol use."*

- The practitioner should discuss with Sue the sort of information that her carer may want/need and then agree what kind of information she is happy to be shared, and what she wants to be kept confidential. If, for example, alcohol use is an important factor in Sue's illness, but she does not want any discussion of her drinking habits with her carer, it may still be possible for her doctor or CPN to talk about the general advice on alcohol for people with Sue's illness, as long as she has agreed that information about the type of illness can be shared.

However, everyone should take care to avoid the difficult situation that can arise if information is given on the basis of "don't tell Sue I told you this". Professionals must be careful to ensure that the carer

<sup>1</sup> An investigation into the care and treatment of Mr N [http://www.mwscot.org.uk/media/89127/mr\\_n\\_report.pdf](http://www.mwscot.org.uk/media/89127/mr_n_report.pdf)

understands when they are talking about Sue, and when they are talking about information to do with the diagnosis, or the medication for that illness, but which may or may not apply to Sue.

- If Sue is willing to give limited consent to sharing information, it is essential that staff follow her wishes in this respect. It may reassure her to be offered the opportunity to take part in any meeting between staff and carers, to see that the limits on her consent are not being breached.
- It may also be helpful in some situations if agreement is reached that her carer speaks with a member of the team who is not the person with whom Sue works directly or most closely.
- When it seems clear to the care team that it would be in Sue's best interests to share certain information with her carer, but there is an issue that is particularly fraught, it may be helpful to come to an agreement that the carer will not be involved in that particularly sensitive or contentious matter – for example, if someone is reluctant to take medication, or suspicious about it, it may be better to rely upon professional staff rather than the carer to deal with prescriptions and supervision of taking medication.

Practitioners may ask an individual for consent on a single occasion, and then assume that his consent or refusal holds forever. This is rarely the case. As people who are ill recover, their views may change.

- Practitioners should have ongoing discussions with individuals about the value of involving their carers and should be regularly reviewing issues of consent with them.

### **Breaching confidentiality – what does this mean?**

Occasionally, the practitioner may be justified in sharing information with a carer or third party, **without the individual's consent**, if the sharing of the personal information is to prevent serious harm to either the service user or others.

### **GMC guidance**

*"Disclosure of personal information without consent may be justified in the public interest, where failure to do so may expose the patient or others to death or serious harm."*

*"You must weigh the possible harm (both to the patient and the overall trust between doctors and patients) against the benefits which are likely to arise from the release of information."*

The GMC's guidance also says:

- That, if the doctor thinks that disclosure in the public interest is necessary, he or she should seek the individual's consent, if practicable. If the doctor does not get the individual's consent, he or she may disclose relevant information, if the risks of not disclosing it are serious enough. The guidance makes a distinction between consent not being sought, and consent being sought and refused.
- If it is not possible to seek the individual's consent, because he or she lacks capacity (or cannot be contacted), and there is a serious risk to either the individual or others, the practitioner should disclose the relevant information. In our view, disclosure would be justified in the interests of the individual, if it could prevent serious harm to his or her health, welfare and safety.
- If the individual's consent is sought and he or she refuses, the practitioner should only breach confidentiality if there is a serious risk to another person. Circumstances in which the practitioner could breach confidentiality, in spite of the individual's refusal, would include the prevention of a serious crime, especially a crime against the person. In our view, the practitioner should warn carers if he or she believed that there was a serious risk that the individual might harm a carer or someone else in the family or neighbourhood. Depending on the seriousness of the risk, he or she should also consider informing the police.

In considering whether to disclose information without the individual's consent, it would be good practice for the practitioner to consult with the clinical team and record his or her reasons for deciding to go ahead with disclosure. If possible, it would also be desirable to inform the patient before disclosing the information.

In practice in this kind of situation the practitioner must consider the legal position – Data Protection, Child Protection – as well as appropriate employment/professional codes of conduct, and may wish to consult with their own professional body.

## WHEN AN INDIVIDUAL LACKS THE CAPACITY TO CONSENT TO THE SHARING OF INFORMATION

An individual may lack capacity to consent to the sharing of information about them because of the effects of their mental illness, learning disability or other related condition. For some individuals their capacity may be permanently impaired and for others their capacity may be temporarily or intermittently impaired. Capacity is not an all or nothing concept. It can vary with time – even the time of day in some individuals – and can vary markedly in some people with a mental illness who have episodes when they are very well, but also times when they are very acutely unwell.

*The AWI Codes of Practice and the GMC ( "Confidentiality" s 57-62 and in "Consent: patients and doctors making decisions together") give guidance on this.*

The principles of AWI state clearly that any level of capacity the individual does have, and any views they voice, or have previously made known, must be taken into account.

The GMC guidance outlines safeguards for practitioners to consider in deciding on an appropriate extent of information-sharing with a carer *making the care of the patient the first concern*.

### Adults with Incapacity (Scotland) Act 2000 (AWI) – Guardianship and Power of Attorney

Relatives, carers or sometimes another party (usually the local authority SW) can get legal powers from a court (**guardianship**) to make certain decisions or take responsibility for certain actions for an adult with incapacity; this can also include the power to access medical records.

*"Bill has dementia and his daughter is his main carer. He no longer has capacity. His daughter could apply for a **guardianship** order with appropriate powers. Professionals involved in Bill's care should be ready to provide the necessary information to her about this, and guide her to appropriate support if she is considering making an application. If it is clear that Bill is unlikely to develop or regain capacity, then in many cases this is a discussion that professionals should open up with his daughter if it would be likely to be in his best interests if she had these powers.*

*If Bill's daughter does have these powers, this should be made clear to staff involved in his care, and set out clearly in his records/care plan, so that all staff involved in his care are absolutely clear about their legal duty to fully inform and consult with her.*

An individual who has the understanding of the nature and extent of the powers he or she is granting may give **power of attorney** (POA) to a trusted person(s) [who may be a relative or carer] in the event that they lose their ability to make their own decisions. This can be for financial matters (continuing POA) or welfare matters.

*Hanif is someone who has a mental illness which causes him to have times when he loses capacity. He can, while well enough to do so, grant his carer POA. It would be his decision what powers to grant; if he chose to include the power to make decisions about medical treatment, his carer/POA must make sure that staff involved in Hanif's care know this and they in turn must ensure that they keep the carer/POA fully informed and consult with them.*

*Again, Hanif could choose to include a specific power to access part or all of his medical records, or to do so in particular circumstances. Professionals involved in his care should ensure that he understands fully the possible consequences of granting such a power.*

*Many people choose to grant power of attorney, often to relatives or friends, as a precaution for the possibility of losing capacity later in life (for example if they develop dementia).*

## **Some other circumstances:**

### **Young people**

*The GMC provides special guidance for doctors about confidentiality when the patient is aged under 18. [See 0-18 years: guidance for all doctors]*

**In Scotland**, any person over the age of 16 is presumed to have capacity and to be able to make decisions about their own health care and also about the sharing of personal health information [the Age of Legal Capacity (Scotland) Act 1991].

If a person over the age of 16 does not have this capacity then AWI is the law which sets alternatives in place, and mental health professionals will only be bound to share health information if the carer also has appropriate guardianship powers.

- Any young person over the age of 12 is taken to be capable of decision-making about their own health care and sharing of personal health information *unless there is evidence to suggest otherwise*. It is the responsibility of the health professionals involved to satisfy themselves about this – so, unless there is evidence to suggest a young person aged 12-16 is not able to understand well enough to make these decisions, a health professional should generally only disclose information with the consent of the young person involved.
- In the case of any child or young person under 12, if the health professional is sure that they do have enough understanding about their own health-care decisions, and about sharing of information, then sharing of information should only be with the consent of the young person.
- The guidance available to health professionals highlights the need to assess the understanding of any young person in terms of the particular situation or treatment (for example they may be capable of making an independent decision about a relatively simple health matter but not about something more complicated that may affect them in later life).
- When a young person under 16 has not yet developed capacity for health-related decisions, the person who has parental responsibilities is generally the person who has the power to make those decisions, and health professionals would be expected to share information with them – with the same safeguards as above where an adult has impaired capacity but has some understanding and can make some views on the matter known.

Health professionals must always be mindful of any Child Protection issues that may influence these decisions.

## Parent-carers

When we consulted carers about this guidance, they stressed the particular concerns of 'parent-carers'. Parents generally have anxieties about their children progressing to adulthood but when a young person has a learning disability, or has developed a mental illness in childhood or adolescence, these worries and concerns are so much greater.

Just because someone is a parent, however, does not give them the legal powers to continue making decisions for their children into adulthood, even though their children may continue to need their help and support. This is a very difficult and uncertain time for parents and one when they should often seek legal advice.

It is beyond the scope of this document to cover the wider issues about best practice for mental health professionals and parent-carers working together through transition to adulthood and adult services. Trying to achieve the right balance of independence and support, freedom and protection is daunting for parent-carers, mental health professionals, and paid care/support workers alike.

Where it is likely that a young person will not develop the ability to make health-care decisions (or will do so on a limited or delayed basis), a parent-carer may wish to seek these powers on their son or daughter's behalf through AWI welfare guardianship. If they are doing so, they may also wish to consider seeking the power to access their son or daughter's medical records.

## Complaints

Sometimes when carers contact us they are unhappy about the care and treatment of the individual concerned, and they may want to make a formal complaint. Because of Data Protection and confidentiality issues, generally service managers will need the consent of the individual to proceed and share the outcome of any investigation into a complaint with a carer (this is often called a 'mandate').

This can cause real difficulties if the individual does not have capacity to consent.

If the carer has proxy powers under AWI (power of attorney or guardianship) covering health-care decisions and access to records, they have the right to make a complaint and to see the outcome. If the individual has previously indicated their wishes or is able to make views known, the service may take that as sufficient authority to undertake some level of inquiry but may not be able to share the outcome with the carer.

We believe that individuals should not be disadvantaged on the basis that they are not able to make a complaint on their own behalf. We would expect service managers to consider situations on a case-by-case basis to make sure any concerns about vulnerable individuals were not being overlooked. Independent Advocacy can be useful in this situation.

Sometimes the MWC hears about a situation like this, and we make our own enquiries. When we do this, if we are satisfied that there is no cause for concern, and that there has been no deficiency in the individual's care and treatment, we will take no further action. If we have concerns, we will pursue the matter until we are satisfied that the necessary action has been taken. However, without consent from the individual, we generally cannot share the outcome of our enquiries with the caller or carer.

## Mental Health (Care and Treatment) (Scotland) Act 2003

Section 250 of the *Mental Health (Care and Treatment) (Scotland) Act 2003* introduces the safeguard of **named persons**. If an individual is or has been detained under the Mental Health Act they can choose a named person to protect their interests. A named person can be anyone aged over 16 who is not directly involved in a professional role in the individual's care. The named person has a right to be consulted about aspects of the individual's care and treatment; they can also make applications to the Tribunal and attend and give their views.

An individual can choose their own named person. If they do not choose one or are too unwell to do so, a carer or relative will automatically become the named person. If the individual detained is under 16, the named person will automatically be the parent or guardian, the local authority or carer.

If the individual has formally nominated their carer as their named person and understands the implications of this decision, then there should be little difficulty for practitioners or hospital managers in meeting their obligations to disclose the information required by the Act.

Mental health officers (MHOs) have a duty to complete a social circumstances report (section 231 of the Act) following the making of a compulsory order in relation to this Act. Carers may well be contacted for background information by the MHO.

### Potential issues

- A problem can arise when the individual has not nominated someone to act as his or her named person, and his or her primary carer or nearest relative becomes the named person by default, under section 251 of the Act. The individual may object to the carer being given the information required by the Act. Under section 253, they can make a declaration removing the named person. However, many people are too unwell to do this, or may be unwilling to do it. In this situation, practitioners and hospital managers have to balance their statutory obligations under the Act against their duty of confidentiality to the individual and also his or her right to privacy under Article 8 of the ECHR.
- Another issue of particular concern to carers and relatives can be if the individual chooses someone else as their named person. With a couple of exceptions, they can choose whoever they like to be their named person. If you think that the choice of named person is inappropriate, you can apply to the Mental Health Tribunal to have the nomination reviewed. The tribunal will make whatever decision they think is in the individual's interests.

Sometimes the duty of confidentiality clearly outweighs the requirements of the Act, because giving the information to the carer could seriously harm the individual. For example, there may be evidence that the carer has abused them and that giving him or her information about their compulsory care would increase the risk of further abuse. Unfortunately, most circumstances are less clear cut and decisions have to be made on a case-by-case basis.

The decision whether to withhold statutory information from the named person should be made in consultation with the clinical team and involve the individual as much as possible. It may also be appropriate to seek legal advice. The reasons for withholding the information should always be recorded.

**If the person has chosen to go into hospital voluntarily, the rights of a named person do not apply.**

Section 275 of the Mental Health (Care and Treatment) (Scotland) Act 2003 introduces the provision of **Advance Statements** in respect of medical treatment. We would view a statement of wishes about information sharing as something separate from these provisions. However, including such a statement in the individual's personal plan or crisis plan may be helpful for carers and professionals involved and may help with issues of information sharing if the individual later becomes unwell.

### **Carers supporting people with chronic mental illnesses or learning disability may need to get support from other carers.**

It can be very stressful being a carer and carers supporting people with chronic mental illnesses or learning disability may find it helpful to get support from other carers in similar situations. It is the support of sharing experiences and problems with other carers who have a real understanding of what they are going through that is often most helpful. Clearly a carer cannot get this support without sharing personal details about the individual and his or her condition – they should, however, consider how they would feel about such information being shared about them and respect the individual's right to privacy.

As stated previously in this document, there is no express requirement that a carer must respect an individual's confidentiality but we believe they should respect their right to privacy. We think that carers should try to get the individual's consent to talk about his or her situation, provided he or she has the capacity to give it.

When an individual does not have capacity to consent to sharing information the principles of the Adults with Incapacity (Scotland) Act 2000 may provide some helpful guidance to carers.

- The individual's past and present wishes and feelings about his or her privacy should be taken into account
- Other people who know him or her well should be consulted about whether to share information about him or her
- The information should only be shared if it will benefit the individual
- The carer should share only the minimum information that will achieve that benefit.

We have heard carers discussing sensitive personal information about their sons, daughters, wives and husbands in a variety of situations, including public meetings. Cases also come to our attention in which carers have tried to publicise shortcomings in care by taking their story to the newspapers.

Increasingly, there are concerns about breaches of the privacy and confidentiality of individuals with learning disability or mental illness through social media such as Facebook and Twitter and also through on-line self-help resources. We would urge caution in this area due to the potential for information to be passed on without any control.

It is understandable that carers may become frustrated by the shortcomings in mental health or learning disability care, and wish to improve things for the individual concerned. Publicising personal details about the individual without his or her consent, however, could be considered to show a lack of respect for them and their rights. It could also deter practitioners from collaboration with carers.



## CONCLUSION

The introduction of The Mental Health (Care and Treatment) (Scotland) Act 2003 and the Adults with Incapacity (Scotland) Act 2000) has challenged service providers and individual practitioners to involve carers more in the care and treatment of people with mental illness, learning disability and related conditions.

We hope that both practitioners and carers continue to develop new ways of working together to help individuals. Issues of confidentiality should not be a bar to the development of a fruitful partnership between practitioners and carers.

The Commission has a duty to both monitor the operation of these Acts and promote the observance of their principles. We therefore also have a part to play in promoting practitioner-carer collaboration. As part of our work, we regularly talk to individuals, carers, practitioners and service providers across Scotland about how carer involvement is being developed. We are committed to promote and share good practice in doing this well.







Thistle House  
91 Haymarket Terrace  
Edinburgh  
EH12 5HE  
Tel: 0131 313 8777  
Fax: 0131 313 8778  
Service user and carer freephone:  
0800 389 6809  
[enquiries@mwscot.org.uk](mailto:enquiries@mwscot.org.uk)  
[www.mwscot.org.uk](http://www.mwscot.org.uk)

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