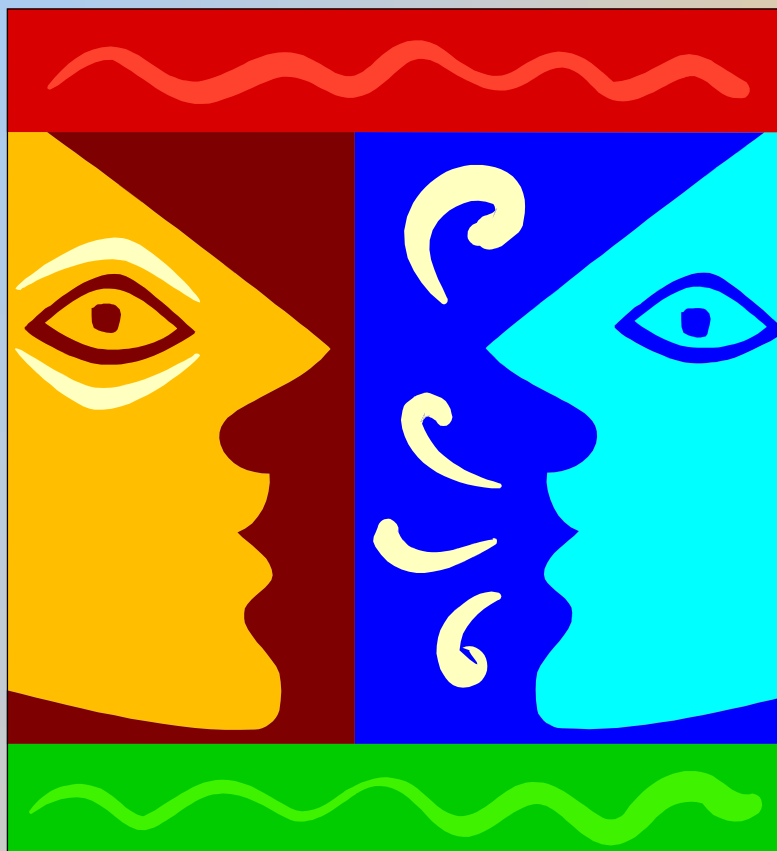


# **Confidentiality in Mental Health**

**A guide to good practice in  
information sharing**



***For all those concerned with  
Mental Health.***

## **Introduction**

In April 2003, Suffolk Carers Mental Health Project hosted a regional conference on the subject of confidentiality and the difficulties with information sharing within Mental Health.

We were already aware, through work undertaken with Carers that this was a major issue. Many Carers reported to us that they often felt isolated, undervalued and marginalised because of poor information sharing.

We began, through our training programmes with Mental Health Workers to explore this in more depth and it became obvious to us that this was in fact as difficult for Professionals to work with as it was for Families. Workers stated that there were no clear guidelines on confidentiality except for their own codes of practice which appeared to constrain them rather than giving them confidence in their own ability to assess each situation on its own merits.

Many also stated that they felt there were no clear policies within their own organisations that gave them confidence and that they had to practise defensively in order to protect themselves.

During discussions with staff it became obvious that practise was based on assumptions and no clear directives were given as to when you should share necessary information and when you should not.

Suffolk Carers Mental Health Project decided that this was an issue that needed to be debated by all interested parties ~ together.

To this end the conference was organised to reflect all those stakeholders with an audience of 50% Mental Health Workers, 25% Service Users and 25% Family Carers.

From this day a working party convened and after many hours of hard work by those involved this booklet was developed.

This work has also fed into developing national guidelines in partnership with The Royal College of Psychiatrists and The Princess Royal Trust for Carers.

**Sue Allison**

**Director of Family Carer Services, Suffolk Carers.**

Those who use Health and Social Care Services have the same rights as everyone else to be treated with dignity and respect. This includes the right to privacy, and to have their say in what others are told about them. I am happy to commend *Confidentiality in Mental Health* as an excellent resource for Service Users, Carers and Mental Health Professionals alike. Here you will find information on the legal basis for confidentiality and clear guidelines for good practice. If you are wary of sharing your personal details, there are suggestions about what you can disclose without compromising your privacy, and of what Carers find it helpful to know, without needing to know everything. There is some welcome encouragement for Service Users and Mental Health Professionals to discuss as early as possible what can and cannot be shared. And there is information about Advance Directives, and what Service Users and Carers can expect from the Care Programme Approach.

Service Users, Carers, Advocates and Mental Health Professionals have worked together to produce *Confidentiality in Mental Health*. Its use can only encourage greater responsibility in what is a very sensitive area. To this end it deserves the widest possible circulation.

**John Parr**  
**Advocacy Manager**  
**East Suffolk Advocacy Network.**

I am very pleased to provide one of the introductions for this guide to confidentiality in mental health. It is a very difficult and changing area which presents real difficulties for people who have been involved in mental health care for a very long time.

The challenge it must pose for people who are new to mental health issues must be great and the availability of a straightforward guide like this is a real boon. Suffolk Carers Association are therefore to be congratulated on having facilitated the producing of so clear and informative a guide.

I am also grateful that staff from the Partnership Trust were involved in preparing the document. The guidance is the product of a very wide group of people involved in mental health care. Therein lies much of its strength – that it covers the subject from all angles and does so in the plainness of English which commends itself to the ear.

The Partnership Trust works hard (sometimes with mixed results) to work well with Service Users and their Carers. For some of us it is a natural way of doing things, for others of us it is a difficult skill and something strange and very different from what our training and experience has led us to understand and practise properly.

Therefore I hope everyone who has a copy of this manual uses it well. This includes the Trust's staff in helping them not just think through the issues of confidentiality but to understand those issues from the Service Users' and from the Carers' point of view. I hope Service Users and Carers find it helpful in understanding their rights and responsibilities within the confidentiality labyrinth of mental health care.

I hope that the agencies themselves continue to reflect on the needs of people with mental health problems, on the demands those problems place on Carers and families and conclude that it demands that we continue to support these kind of initiatives where all partners come together to provide clear authoritative and unambiguous support for Service Users and their Carers.

**Mark Halladay**

**Chief Executive ~ Suffolk Mental Health Partnership NHS Trust**

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## **Definitions of Terms used within this booklet:**

**Carer** – a relative or friend who provides or intends to provide a substantial amount of care to a Service User/Patient on a regular basis, but not necessarily through living with them.

**Service User/Patient** – someone who uses or has used health and/or social care services because of mental illness or disability.

**Health Care and Social Care Professionals** – everyone working in mental health care in a professional capacity including GP's who are usually the first point of contact for people experiencing mental illness, although for some people the police may be the first point of contact.

**An Advocate** – someone who supports Service Users or Carers by helping them to put their views forward and ask their own questions.

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## **PARTNERS IN CARE**

The Royal College of Psychiatry and the Princess Royal Trust for Carers have worked together in a year of partnership (2004). One of the main aims of the campaign is to show that if all those involved in the care of people with mental health problems and learning disabilities can work together, a trusting partnership can develop between Carers, Service Users and Professionals which will be of benefit to all.

Please find below details of some of the leaflets that relate to confidentiality and information sharing:

- Carers and confidentiality in mental health ~ issues involved in information sharing.
- A checklist for Carers of people with mental health problems.
- A checklist for people with mental health problems.
- A checklist for psychiatrists.

For copies of the above mentioned or details of other materials produced by the Partners in Care Campaign please contact the External Affairs Department, Royal College of Psychiatrists, 17 Belgrave Square, London, SW1X 8PG. Tel: 020 7235 2351

These can also be downloaded from [www.partnersincare.co.uk](http://www.partnersincare.co.uk)

# **LEGAL REQUIREMENTS.**

## **INTRODUCTION**

There are a number of legal issues surrounding the theory and practice of sharing information about a person who is receiving a service from Health and Social Care Services. Inevitably, there is some conflict between the need to respect the confidence of those about whom personal information is held and the desirability, and sometimes necessity, of sharing information with professionals, family members and Carers in the interests of an individual, their family or the wider community.

The various legal frameworks within which users of mental health services and their families and Carers (both professional and informal) operate are covered below. The aim of this guide is to provide a general indication of the legal obligations placed upon individuals in given circumstances. However, in cases of doubt it will be necessary to seek specific legal advice. The local Mental Health Act Administration Team (based at your local mental health in-patient unit) would be able to provide a list of local advocates who have specific mental health knowledge.

## **PRIVACY**

### **Duty of Confidentiality**

Historically, there has been a general presumption of confidentiality, i.e. that the confidentiality of information disclosed by one person to another in circumstances where it is reasonable to expect that the information will be treated as confidential, will be respected. Where the duty of confidentiality has been breached in circumstances where it was not appropriate to do so, an aggrieved party may make a formal complaint (e.g. to the General Medical Council, Nursing & Midwifery Council or via Suffolk Mental Health Partnership NHS Trust or Suffolk Social Care Services Complaints procedures.) The courts have, in various cases brought by aggrieved parties, upheld the general principle that there is a duty of confidence. However, there was no specific statutory (legal) right until the Human Rights Act 1998 was enacted.

Each NHS Trust has its own Patient Advice & Liaison Service (PALS) which can be contacted for support and information if Service Users are experiencing difficulties in relation to information sharing or service issues.

## **Human Rights Act 1998**

Article 8 of the Human Rights Act 1998 created the first legal right to privacy, giving each person "the right to respect for his private and family life, his home and his correspondence." However, "public authorities" (which includes Health and Social Care Services workers acting in the course of their employment) can override that right. Where it is in the public interest, the right to respect confidentiality, for private and family life, may be breached, including in the interests of public safety and for the prevention of crime or the protection of health.

## **Data Protection Act 1998 (DPA)**

By far the most important legislation concerning the privacy of personal information is the DPA, which now covers all records, whether held on computer or in paper. The DPA introduces "Data Processing Principles" which include, amongst other requirements, the duty to deal with personal information fairly and accurately. The collection, retention and sharing of information (or data) are referred to as "processing." The DPA creates the right, subject to certain exceptions, to ensure that information about a person is not "processed" without the subject's consent, unless certain limited exceptions apply.

"Sensitive personal data" is defined as: 'information about racial or ethnic origin, physical or mental health or condition, and sexual life'. It is given the most protection under the DPA. To process such data various conditions must be met, one of which is that the processing is necessary for "medical purposes", which is not defined exhaustively but which includes preventative medicine, medical diagnosis, medical research, provision of care and treatment and the management of healthcare services.

The Information Commissioner (01625 545745) is responsible for overseeing the working of the Data Protection Act throughout England and Wales, and will consider complaints by any person aggrieved by the way in which personal information has been used or withheld.

## **Caldicott Guardians**

An investigation carried out on behalf of the Department of Health in 1997 found that the implementation of confidentiality and security requirements was patchy across the NHS. As a result a network of "Caldicott Guardians" was established to oversee the use of patient information in each NHS Trust.

The Caldicott Guardian is responsible for agreeing and overseeing local information sharing protocols and resolving issues that arise concerning safeguarding the privacy of information and sharing of information. He or she will, if necessary, refer issues to the complaints procedure Information Commissioner.

## **SHARING INFORMATION WITH THE DATA SUBJECT (THE INDIVIDUAL)**

### **Data Protection Act (DPA) 1998**

The DPA gives data subjects the right, subject to certain exceptions, to receive information about themselves held by a Health Trust, Strategic Health Authority, Social Care Services department and/or local social housing provider.

However, there are exceptions to this right in respect of information about a person's health where, in the opinion of the person or body holding the information, the disclosure would be likely to cause serious harm to the physical or mental health or condition of the data subject or any other person.

Social work records are exempt from this obligation where disclosure would be "likely to prejudice the carrying out of social work". This means that serious harm to the physical or mental health or condition of the data subject or any other person is thought likely.

### **Code of Practice Mental Health Act 1983**

The Code informs Hospital managers of their statutory duty to give information to detained patients, and to their nearest relatives, unless the patient objects. All patients should be given information to help them understand why they are in hospital, or subject to guardianship.

## **SHARING INFORMATION WITH OTHERS**

### **Data Protection Act 1998**

Ordinarily, personal information held by an NHS Trust or Social Care Services department cannot be shared without the consent of the person

to whom the information relates. However, there are certain circumstances where information sharing without consent is permitted:

**Children/Young People** - Where a child or young person does not have sufficient understanding to make his or her own request, a person with parental responsibility can make the request on the child's behalf. Where a parent applies on behalf of a child, an authority should be satisfied that the child lacks ability to make a valid application, or has capacity and has authorised the parent to make the application. Where the child does not have ability, the relevant authority also needs to be satisfied that the request made by the parent on the child's behalf is in that child's interest.

**Mental Capacity** - If a person lacks capacity to manage their affairs, a person acting under an order of the Court of Protection or acting within the terms of a registered Enduring Power of Attorney can request access on her or his behalf. Mental disorder does not equate with mental incapacity and many people suffering from the former may have sufficient capacity to enable them to deal with their own affairs, in this case their consent to disclosure would ordinarily be required.

**Legal Obligation to Disclose Information** - Where the disclosure of personal data is necessary in order to comply with a legal obligation imposed on an authority, the consent of the data subject is not necessary. Authorities should, however, inform the subject that such an obligation exists.

**Staff and Other Agencies** - An authority may disclose personal information to staff directly involved in a case, and their line-managers, strictly on a need to know basis. An authority may also disclose personal information to anyone else who cares for one of their clients, for example, a voluntary body or care provider, where the information is, or is likely to be, needed for the purposes of that care. This would include any independent providers with whom the authority has a contract to provide care.

### **Mental Health Act 1983**

An Approved Social Worker (ASW) making an application for admission to hospital of a patient under a Section of the Mental Health Act (MHA) must "where practicable" inform the Nearest Relative of the patient of the admission (as defined by the MHA).

Where an application is made by an ASW for treatment, the ASW must, "where practicable", consult with the nearest relative.

## **Code of Practice Mental Health Act 1983**

Where a patient is mentally incapacitated their position should be explained to them as far as possible, and their close relative, Carer or advocate should be kept informed about the arrangements for their care.

The Code states that "ordinarily, information about a patient should not be disclosed without their consent. Occasionally it may be necessary to pass on particular information to professionals or others in the public interest, for instance where personal health or safety is at risk."

### **FURTHER INFORMATION SOURCES**

Guide to the Data Protection Act 1998 for NHS staff (DoH website)  
<http://www.dh.gov.uk/dpa98/>

Data Protection Act 1998 – Guidance to Social Services (DoH website)  
<http://www.dh.gov.uk/pdfs/datap.pdf>

Information Commissioner's website:  
<http://www.dataprotection.gov.uk>

NHS Code of practice re confidentiality (DoH website)  
<http://www.dh.gov.uk/policy&guidance>

British Medical Association (BMA website)  
<http://www.bma.org.uk>

Nearest relative: a definition and rights (National Electronic Library for health website)  
<http://www.nelmh.org>

Department of Health & Welsh Office ~  
Mental Health Act 1983 – Code of Practice.

### **LEGISLATION**

Mental Health Act 1983 (sections 2, 3, 11, 26)

Human Rights Act 1998 (schedule 1, Art. 8)

Data Protection Act 1998

The Data Protection (Subject Access Modification) (Health) Order 2000

The Data Protection (Subject Access Modification) (Social Work) Order 2000

Carers & Disabled Children's Act 2000

Carers (Equal Opportunities) Act 2004 (England & Wales)

For consideration: Mental Capacity Bill.

A copy of the bill & explanatory notes is available from:

<http://www.hmsso.gov.uk/acts/acts2004>

Copy of legislation can be viewed at [www.hmsso.gov.uk](http://www.hmsso.gov.uk)

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## **Good Practice Guidelines**

### **Background**

It is unfortunately common for Carers who wish to discuss the person they care for, who has a mental illness, with a member of the Mental Health Team, to be told that this is not possible because of "patient confidentiality". The Carers may wish to provide information they believe would be helpful for treatment or which might prevent worsening of the person's condition. They may want to offer care in hospital, want advice on how best to care, how best to deal with unusual behaviour, or seek advice to help them cope better with the impact of the illness on themselves, or others. Carers may lack basic knowledge about the illness, or may not even know to whom they can turn for help. If a person expressly bars contact with the Carer, Mental Health Professionals often find it difficult to decide when to breach confidentiality.

Easily understandable, accurate and timely information should be provided by health care professionals and be made freely available to Service Users and Carers, from the onset of any illness and throughout its course especially relating to:

- The illness
- Treatment, including medication, talking treatments and side effects
- Their rights e.g. legal, civil and human rights etc
- The availability of services, including advocacy, and how to access them
- How to cope with the effects of mental illness
- Help available for any sexual or spiritual problems, diet, smoking, and drug and alcohol addiction problems (known as 'dual diagnosis' when combined with mental health difficulties).
- Where to obtain information and support in the community e.g. benefits, personal finance, housing, employment and the voluntary sector.

The advantages of sharing information with Carers should be explained to Service Users, e.g. to enable their Carer to support them effectively. If

they are unwilling to share information when they first become unwell, they should be encouraged to do so, when in better health.

Personal information about the health of a person with a severe mental illness should not be shared with other people without their consent unless there are justifiable grounds on a "need to know basis". For example:.....

- Patient safety, risk of harm to themselves or others i.e. will the patient's healthcare be compromised if information is not shared?
- In the public interest/to protect the public, e.g. in order to prevent serious crime, support detection, investigation and punishment of serious crime (see below) and / or to prevent abuse or serious harm to others.

"The definition of serious crime is not entirely clear. Murder, manslaughter, rape, treason, kidnapping, child abuse or other cases where individuals have suffered serious harm may all warrant breaching confidentiality. Serious harm to the security of the state or to public order and crimes that involve substantial financial gain or loss will also generally fall within this category. In contrast, theft, fraud or damage to property where loss or damage is less substantial would generally not warrant breach of confidence." (NHS Confidentiality Code of Practice, Department of Health 28.07.03)

Serious crime, as defined by the General Medical Council is "a crime that puts someone at risk of death or serious harm and would usually be crimes against the person, such as abuse of children" (General Medical Council guidance "Confidentiality: Protecting and Providing Information paragraph 37).

### **The Mental Health Act 1983 Code of Practice**

The Code of Practice provides guidance about information sharing in relation to mental health care.

Private confidences from Service Users to staff should not be shared with their Carers unless a risk assessment clearly indicates potential harm for individuals concerned.

Personal information provided by Service Users should only be shared with people who need to know it.

Particular care should be taken not to pass on damaging information without good cause, e.g. details of criminal history, except where this suggests continuing risks, e.g. of serious violence.

If a Service User does not wish their Carer to be given information about them, the Carer should nonetheless be offered:

- An explanation of the confidentiality protocol of the hospital, service etc.
- Information that is not confidential, e.g. general information relating to the safeguarding of the Service User's general well-being and details of organisations that provide information and support.

<p><b>LISTENING AND PROVIDING GENERAL INFORMATION DOES NOT BREACH CONFIDENTIALITY PROTOCOLS.</b></p>
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There may be occasions when Carers need to talk to professionals without the person they care for being present. Professionals should make this possible. Information given by Carers in confidence at meetings or in writing should not be passed on to the Service User without the Carers consent, but Carers should be encouraged to share information with the person they care for when it is appropriate.

### **Issues of Information Sharing and the Mental Health Act**

Service Users should be informed of their right to see their health records under the "Access to Health Records Act, 1990", and the procedures and time limits for responding to their written applications to see them, subject to some exceptions, for example:

- Information which might identify a third party, where access would not be in accordance with the best interests of the Service User.

Hospital managers have a duty to provide detained 'patients' under a section of the Mental Health Act with information, to enable them to understand why they are being detained, and about their rights to a Mental Health Review Tribunal.

Information on 'rights' is given to the patient on admission or as soon as appropriate, by nursing staff. Rights procedure is reinforced on a weekly basis. If a patient wants to appeal against his/her detention the Mental Health Act Administrator will explain the appeal procedure in more detail. This explanation will inform the patient from whom reports may be

requested from, and the patient and his legal representative are given copies.

The patient is always asked if he/she wishes his nearest relative to attend and they would not be invited to attend without the 'patient's' consent. (Mental Health Act '93)

Service Users should be informed if information has been disclosed to people who need to know it.

Advance Statements (see relevant section) prepared when the Service User is mentally stable should be used to enable Service Users to specify to whom information may be disclosed when they are unwell and/or require going into hospital.

There may be times, when Service Users are acutely unwell, when it may be necessary to disclose information about them without their permission. A reasonable attempt should be made to encourage them to share information before it is disclosed to people who need to know it.

Everyone, including Carers, providing care either regularly or intermittently should know the outcome of any assessment of risk.

Care must be taken when giving information about diagnosis as this can lead to stigmatisation and stereotyping of Service Users.

Service Users should be consulted before decisions are taken about their treatment and care.

Carers of detained 'patients' should be told of their rights and be informed when the 'patient' is to be discharged from hospital (as long as the patient does not object). They should also be given information about the "Mental Health Act".

Service Users should be encouraged to share information with their Carers to help them understand, for example, the side effects of the medication they are taking; they could then discuss with them issues such as "drug holidays" and alterations in medication.

It is good practice for Carers to share information with Service Users and help them to obtain and understand the information that they need to know.

All agencies and professions providing mental health services should ideally have a similar approach to sharing information, recognising that some personal information needs to be shared between agencies to

enable effective services to be delivered. Information should be shared speedily so there is no gap in services e.g. on discharge from hospital.

Gossip about Service Users or Carers is unacceptable.

During a series of workshops on confidentiality and information sharing the following points were made:

Within a Family, more than one person may identify themselves as an interested party and it can be difficult for Professionals to be clear about who should know what. We would suggest that a 'communication tree' would help clarify this. This 'tree' clearly states, acting on information from the Service User, who would be the main point of contact and that other members of the family are told this and would obtain information from this identified person.

Representatives from this group also had some very clear ideas about how information sharing and confidentiality could be made simpler. If at the very beginning of every therapeutic relationship, the Practitioner and the Service User agree on what information should stay confidential, then once this has been agreed it would enable all other general information pertaining to the illness to be shared. This needs to be reviewed regularly to ensure that confidence is maintained.

Confidentiality also relates to Carers talking to Professionals about the person that they care for. As for the Service User, it should be agreed at the earliest opportunity what information is confidential and what can be shared.

## **Frequently asked Questions and Answers ~**

### **Q Why is information sharing so important?**

**A** Because so many people, including friends and families, may be involved with providing care, they need to collaborate closely with each other to be able to do so effectively. It is vital that health care professionals listen to Carers and Service Users.

### **Q Why is information so important for Service Users?**

**A** For a number of reasons including reducing their level of anxiety. Having a severe mental illness can be very frightening and fear of the unknown adds to feelings of anxiety and loss of control caused by illness. Knowledge can empower, but ignorance can lead to fear.

It also helps Service Users to better cope with their illness, its effects and treatment.

Being able to discuss their circumstances and the help they need on a level footing with professionals boosts self esteem and aids recovery.

Being able to access the help they need is only possible with the right information.

They need to know their rights e.g. legal, civil and human rights etc for their own safety and well-being.

Information helps them understand their treatment, its benefits and potential side effects.

**Q Why is information so important for Carers?**

**A** For most of the same reasons as for Service Users; Carers generally seek to help the person they care for in a way that suits them best; they should not have to learn from their mistakes made through lack of knowledge.

Carers should be encouraged to share information with professionals such as acts or threats of harm to themselves or others, abnormal behaviours, suicidal thoughts and also positive achievements.

Professionals should listen to Carers concerns in order to prevent the tragedies that have occurred in the past. Carers usually know the Service User better than anyone else.

**Relevant information from all (Carers, Service Users and Mental Health Professionals) should be shared in order to enhance the recovery of the Service User.**

**Q Why is information sharing so important for Health & Social Care Professionals?**

**A** To achieve the best outcome for everyone: Service Users, Carers and professionals need to work together as a team.

**Q Do Service Users have an absolute right to confidentiality?**

**A** No, they have a right to confidentiality of personal information, which may need to be overridden through concern about their welfare and safety and that of other people.

**Q How should information be provided?**

**A** Both in writing and verbally. Written information should be factual and provided in plain English and in other languages, when needed, supplemented by personal explanation. Cultural differences and needs should be taken into account.

**Q When should information be provided?**

**A** Important times for Service Users and Carers to be given information include:

- to Service Users before medication is prescribed
- to Carers as soon as possible after the onset of illness
- to Service Users and Carers shortly before going into hospital and whilst in hospital to explain how needs will be assessed and the Service Users aftercare planned.
- in preparation for discharge and at the time of discharge from hospital.
- at Care Plan Meetings and appointments

**Q Who should provide the information?**

**A** Health and Social Care Services should routinely provide information that Service Users and Carers need. This can be usefully supplemented by information from Voluntary Mental Health Organisations.

**Q What does the law say about everyone working in mental health care in a professional capacity?**

**A** Everyone working in a professional capacity with Carers and Service Users within Mental Health has a legal duty to keep client information confidential.

**Service Users may be receiving care from other people as well as the NHS. E.g. out of county placements and transfer of care responsibilities to the voluntary sector. These agencies need to share important information so that they can all work together for the Service Users benefit.**

Professionals should only ever use or pass on information if people have a genuine need for it in everyone's best interests ie on a need to know basis. Whenever possible all details which identify the Service User should be removed. Law strictly controls the sharing of some types of very sensitive personal information.

**Q What reassurance does the Service User have if the NHS transfers their care to the Voluntary Sector?**

**A** Independent Providers should provide reassurance via their own policies and procedures, as to the quality of care and good practice elements referred to in this document.

## **THE CARE PROGRAMME APPROACH (CPA)**

The Care Programme Approach (CPA) is used nationally (in England and Wales) by mental health services. It is a way of identifying individual needs and preferred treatment and should be negotiated between the Service User, Care Co-ordinator and any other members of the multi disciplinary team. The consent of the Service User should be sought at each stage of the care planning process and before the final care plan is circulated to all those involved in delivering care. The Service User will be asked to sign the care plan if they are happy with it. If they are unhappy about any aspects, this should be recorded with a reason why. Unnamed professionals may also receive a copy in the event of a crisis.

In 1999, the Department of Health published a National Service Framework (NSF) for Mental Health. Standard 4 states:

All mental health Service Users on CPA should:

- receive care which optimises engagement, anticipates or prevents a crisis and reduces risk
- have a copy of a written care plan which includes:
  - a) the action to be taken in a crisis by the Service User, Carer and Care Co-ordinator
  - b) advises the GP on how they should respond if the Service User needs additional help
  - c) is regularly reviewed by the Care Co-ordinator
  - d) ensures the Service User is able to access services 24 hours a day, 365 days a year

Standard 6 addresses the needs of Carers who provide regular care for those on CPA. Carers should:

- have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis
- have their own written care plan which is given to them and implemented in discussion with them

In practice, whilst Carers are always entitled to an assessment, currently there is no guarantee that there will be services available to meet their identified needs.

CPA was introduced in 1991 and upgraded in 1999, by the Department of Health, as a means of raising standards in mental health care. There are two levels: standard and enhanced. The enhanced level is used for people assessed as having either complex needs or whose care involves several different agencies. The standard level is used for people who only need access to one agency or discipline, or low level or infrequent support from more than one agency or person.

CPA sets out guidelines for good practice, to be used by in-patient and community services from the first point of contact with the service.

A properly developed care plan under CPA addresses all aspects of a Service User's life, including their physical health, housing, occupational, social, financial and leisure needs.

It should also include an emergency or crisis action plan, a risk assessment and may include an Advance Directive (see relevant section). Risks assessed would include risks of intentional or non-intentional harm to self or others and strategies for minimising these risks.

It is not necessary for all members of the multi-disciplinary team to be present at a CPA review meeting. The Service User must always be consulted about who they wish to be present. The Care Co-ordinator may consult others prior to or after the meeting, for example, advocates, relatives, Carers, Occupational Therapists, GPs, Probation Officers, Physiotherapists, Social Workers or anyone involved in providing care. The sharing of information with any of these individuals must be discussed in advance with the Service User.

The Service User has the right to opt out of the CPA process at any time.

Care plans may be stored on paper or electronically. The Service User has the right to their own personal copy. Carers may be given a copy of the plan with the Service User's consent. All professionals are required to comply with the Data Protection Act 1998 and confidentiality policies or codes of practice from their own professional bodies and employers.

Care plan formats are variable. For an example, see appendix.

Professionals work to a set of principles regarding Service User confidentiality known as the Caldicott Principles. These are:

- Justify the purpose(s) for using confidential information
- Only use it when absolutely necessary
- Use the minimum required
- Give Access on a strictly 'need to know' basis
- Everyone understands his/her responsibilities
- Understand and comply with the law

More information about Caldicott Guardians is given under the Legal Requirements section.

Care plans should be regularly reviewed and updated. Typically, this will be every three to six months, although this should be flexible and needs-led. A Service User can request a CPA review at any time.

## **Advance Statements or Directives**

Advance Directives provide a way for the Service User to inform others about how they want to be treated if they lose the ability to communicate, express themselves and understand what they are agreeing to. They are developed in advance at a point when the Service User is stable and well and medical opinion agrees that the Service User 'has capacity' (ie is of sound mind). They can be used by anyone over the age of 18. They can include preferred or rejected medical treatments and the management of financial affairs. The British Medical Association (BMA) Code of Practice uses the term 'Advance Directives' specifically in relation to types of medical treatment which are being refused and which therefore have legal force. For more comprehensive and affirmative statements of the Service User's wishes, including preferred medication or treatment, the term 'Advance Statement' is used. Organisations other than the BMA may use the two terms interchangeably.

The code of practice on Advance Directives published by the BMA indicates that it is good practice to take the wishes of minors into account as far as is possible, even though legally only an adult can make an Advance Directive. The parent or guardian remains legally responsible and may be able to over rule the young person's wishes.

Advance Directives should include the contact details of those the Service User wishes to be contacted when unwell, arrangements for caring for children or other dependants and pets. They may indicate whether the Service User is willing and consents to being medically examined by a

member of the opposite sex and if so, whether a chaperone is expected to be present. They could include religious or cultural views, which are important to the Service User.

Doctors and other professionals need to know the Service User's thoughts and feelings about accepting treatment. An Advance Directive can be a useful means of promoting good communication, mutual understanding and co-operation between the professional and the Service User.

An Advance Directive can be an invaluable tool in an emergency when professionals are involved who do not know the Service User, or their circumstances, and are assessing their needs.

Advance Directives can be prepared with the help of professionals, Advocates, relatives, friends or Carers and tailor-made to the individual Service User and their mental health condition(s).

If the Directive includes details of treatment which a Service User wants to refuse, it is helpful to reinforce this with reasons, so long as these reasons cannot be judged to be illogical or irrational by the courts, by a tribunal or by the Responsible Medical Officer (RMO i.e. the senior doctor responsible for the Service User's care). The Service User may also wish to specify the circumstances in which the refused treatment might be suggested as well as the preferred alternative.

It is a good idea to include details of any medical professionals with whom the Directive has been discussed. To help to communicate the care taken and level of understanding of the Service User, it may also be useful to mention in the text any documents the Service User has read about Advance Directives ~ such as this guide, the British Medical Association (BMA) Code of Practice on Advance Directives or any relevant book or internet site. Although an Advance Directive can be oral, it is always better to make a written statement if possible.

The Service User making the advance statement is expected to be able to:

- Receive (ie understand) and retain information
- Believe it
- Weigh information to reach a decision and
- Communicate his/her decision

**Ideally Doctors and other Professionals who may be involved in the Service User's care should be given a copy, including their GP. There needs to be a clear indicator on the front of the Service Users medical notes that an Advance Directive is in place and when it was last reviewed.**

Currently Advance Directives have no legal status except in relation to specifically refused treatments. Even then, they can be overridden by the Mental Health Act.

Advance Directives or Statements can also be overridden during pregnancy if doctors judge that the foetus is in danger.

Health Professionals are expected to respect the wishes of the Service User and may be called to account – or even charged with assault if they do not. They may also be sued for negligence if they give inaccurate or incorrect information to a Service User while the directive is being drafted. (Source: Janet Sayers ~ Head of Healthcare at Kennedy's Solicitors, London, solicitors to the NHS, nationally recognised for their work around Advance Directives).

There may be circumstances in which the Advance Directive is not implemented, for example, a doctor may feel that the Service User has a new condition which is not covered by the Advance Directive. The doctor might also be keen to take advantage of a new treatment developed since the directive was agreed.

If the Service User has an Advance Directive, this should be regularly reviewed and updated and may become part of the CPA process. It is a good idea for the Service User to tell more than one person outside the professional team that they have an Advance Directive.

Ideally, the Advance Directive should be witnessed by an independent facilitator, although not necessarily a solicitor. It must be stored with the care team, electronically or on paper, in order to ensure it can be accessed and implemented when needed. The Service User may also wish to wear an 'SOS' locket, which indicates that he/she has an Advance Directive and who should be contacted in the event of an emergency.

Carers may find the Advance Directive helpful at times of crisis when dealing with professionals ~ especially professionals not familiar with the Service User.

Whereas the care plan is a negotiated document, the emphasis in the Advance Directive is free expression of desires and preferences by the Service User. In practice, Service Users usually discuss Advance Statements or Directives with professionals and this helps to ensure that they can be realistically implemented. Advance Directives cannot compel doctors to act unlawfully, prevent basic care (the provision of food, shelter and hygiene measures) or expect doctors to give treatment, which they believe to be inappropriate.

It is important that the Service User is not subject to undue coercion or influence by any individual ~ whether a doctor, family or other person. An Advance Statement must be a genuine statement of the Service User's own wishes.

It is good practice for GP surgeries to ask any new patient registering whether or not they have an Advance Directive. As previously stated, the front of the Service User's medical record should be clearly labelled to show that the Service User has an Advance Directive and when it was last reviewed.

It is important that Directives are regularly reviewed as new treatments can make them invalid.

# **APPENDICES**

## **SPECIALIST MENTAL HEALTH SERVICES for ADULTS of WORKING AGE**

### **ASSESSMENT SCHEDULE**

SERVICE USER: NHS No.

ADDRESS: COMPASS No.

N.I. No.

DATE:

ASSESSOR(S):

REFERRAL INFORMATION:

SERVICE USERS VIEW:

MORE DETAILED HISTORY OF THESE PROBLEMS:

OTHER RELEVANT PSYCHOLOGICAL OR PHYSICAL PROBLEMS INCLUDING  
DISABILITIES:

CURRENT SERVICES BEING RECEIVED:

FAMILY HISTORY:

LIFE HISTORY:

FORENSIC HISTORY

SUBSTANCE MISUSE/USE

RELEVANT CULTURAL, ETHNIC AND RELIGIOUS CONSIDERATIONS:

CURRENT DOMESTIC AND SOCIAL CIRCUMSTANCES:

CARERS VIEWS AND NEEDS:

MENTAL STATE:

FORMULATION:

SUMMARY OF ASSESSED NEED:

COMPLETED BY (LEAD) ASSESSOR:

NAME:

DATE:

**Mental Health Partnership Trust  
SPECIALIST MENTAL HEALTH SERVICES**

**SERVICE USER / CARER CARE PLAN**

<b>Surname:</b>	<b>Other Names:</b>	<b>D.O.B.:</b>
<b>Address:</b>	<b>C.P.A. (Delete as applicable)</b>	
<b>Post Code:</b>	<b>Standard</b> <b>Yes / No</b>	
<b>Tel. No.:</b>	<b>Enhanced</b> <b>Yes / No</b>	
	<b>NHS / Compass No</b>	
<b>Assessment / Review Date: (Delete as applicable)</b>	<b>Date Plan to Start:</b>	
<b>Legal Status:</b>	<b>Other Information:</b>	

**OTHER PROFESSIONALS INVOLVED**

Agency / Profession / Carer	Name	Contact Number	Involved with Reviews (y/n)
General Practitioner			

REVIEW DATES			
<b>Date of Next Review</b>			
<b>Date care plan sent to all parties involved*</b>			

\* Where agreed

Retain copy in the notes

<p><b>Your Care Co-ordinator is:</b></p> <p>.....</p> <p><b>You can telephone him / her on</b>.....</p> <p><b>Address:</b></p> <p> </p> <p><b>If you or your Carer(s) have any questions about the help you get, call your co-ordinator. They will be happy to assist.</b></p>	<p><b>Your Care Co-ordinator will:</b></p> <ul style="list-style-type: none"> <li>•Negotiate contact with you and your Carer(s)</li> <li>•</li> <li>•Negotiate contact with the other people who support you and make sure everyone knows what is happening.</li> <li>•</li> <li>•Check that this care plan is working correctly.</li> <li>•</li> <li>•Organise review(s) to see if there are ways of improving the services you get, and to check whether your needs have changed.</li> </ul>
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What I do not want:

- b) In previous situations, this has worked well for me:
- c) In previous situations this has not worked well for me:
- d) My individual needs whilst being cared for are as follows:
- e) Who I would name as an advocate:
- f) Where I would prefer to receive care and treatment

Part 3 – Personal and social statement

Family and friends

- a) Who can / should be informed of my situation:
- b) Who cannot / should not be informed of my situation:

Dependants

- c) I would like to make arrangements for those that I care for as follows:

Pets

- d) I would like to make arrangements for the care of my pet(s) as follows:

Housing / Home

- e) I would like to make the following arrangements for my housing / home care needs

Finances

- f) I would like the following arrangements to be made for my finances

Religious, cultural or faith needs

- g) I need the following arrangements to be made in keeping with my faith, beliefs or culture

Part 4 – Open statement

*Please use this space to include any information or individual needs which have not been included in previous parts of the document*

Part 5 – Declaration

I ..... declare that this document has been completed by myself in accordance with my wishes, at a time when I retain capacity to:

- understand information about treatment options available to me.
- make informed choices and decisions regarding my treatment
- in the event that I become incapable of expressing my choices due to mental health difficulties, it is my wish that this document be referred to as an expression of my choices regarding my mental health care. It is my wish that this document precede all other ways of ascertaining my intent.

I present this document on the understanding that it will be followed where possible and in the event that the choices expressed in this document are not followed, I will be provided with a full explanation when I regain capacity.

Signed:

Date:

Last reviewed:

Next review date:

## **Sources and further reading:**

Living Wills: Advance Directives: The Legal Perspective – paper by Janet Sayers, Kennedy’s solicitors to the NHS, 1997, updated 2004.

Advance Statement: Getting Your Voice Heard - Bradford District NHS Care Trust & the Mental Health Foundation.

Advance Statements About Medical Treatment - BMA Code of Practice 1996.

Confidentiality and Consent – BMA code of Practice.

Caldicott Guidelines – Staff Training Manual Suffolk Mental Health Partnership NHS Trust.

Mental Health – Legal Services Commission (no.22) 2001.

Medical Treatment: Decisions and the Law – Robert Francis QC & Christopher Johnson (published by Butterworths 2001, ISBN no: 0-406-90490-1)

Healthcare Law: Jonathan Montgomery (published by Oxford University Press 2003, ISBN no: 0-19-876574-6)

Planning Ahead: Advanced Statements & Coping Strategies for when you are ill, developed when you are well – (No.13) Manic Depression Fellowship.

Living Wills: A guide for patients – The Patients Association.

Effective Care Co-ordination in Mental Health Services: Modernising the Care Programme Approach – a policy booklet from Suffolk Mental Health Partnership NHS Trust.

The CPA Handbook - The Care Programme Approach Association (CPAA).

Confidentiality & Mental Health – Department of Health.

Policy Statement: Confidentiality – Rethink Severe Mental Illness (No.27).

CPA: Care Programme Approach (CPA Staff Manual) – Suffolk Mental Health Partnership NHS Trust & Suffolk Social Care Services (Dec 2004).

Advance Directives: Notes & Examples ~ course notes for Approved Social Workers – (published by Southend Manic Depression Fellowship 1999, updated 2003).

Advance Planning by People using Mental Health Services – a report by Jim Green for the Mental Health Foundation .

Adherence to Advance Directives in Critical Care Decision Making: Vignette Study – Trevor Thompson; Rosaline Barbour & Lisa Schwartz, British Medical Journal 2003 (in relation to dementia).

The Rights of Informal Carers under a New Mental Health Act – policy statement 26 ~ Rethink Severe Mental Illness website.

Advance Directives, Statements & Agreements and Crisis Cards ~ Rethink Severe Mental Illness (No 51).

Cornwall Road Medical Practice: MIND Advice on Advance Directives.

Seeking Consent: Working with Older People – Department of Health.

Confidentiality: NHS Code of Practice – Department of Health.

Data Protection Act 1998.

Human Rights Act 1998.

Health & Social Care Act 2011 – Section 60.

Crime & Disorder Act 1998 – Section 115.

Airedale Mental Health Advocacy Group.

<http://www.dh.gov.uk/ipu/confidentiality/consent> (DoH)

<http://www.drc-gb.org> (Disability Rights Commission)

<http://www.kennedys-law.com> (Kennedys Solicitors)

<http://www.gmc-uk.org> (General Medical Council)

<http://www.bma.org.uk> (British Medical Association)

<http://www.rethink.org.uk> (Rethink Severe Mental Illness)

<http://www.mind.org.uk> (National MIND)

<http://www.mhf.org.uk> (Mental Health Foundation)

<http://www.mdf.org.uk> (Manic Depression Fellowship)

<http://www.carers.org> (Princess Royal Trust for Carers)

<http://www.carersuk.org> (Carers UK)

<http://www.suffolkmentalhealth.org.uk> (Suffolk Mental Health info)

<http://www.smhp.nhs.uk> (Suffolk Mental Health NHS Trust)

<http://www.suffolkcc.gov.uk> (Suffolk County Council)

<http://www.nimhe.org.uk> (National Institute for Mental Health)

<http://www.rcpsych.ac.uk> (Royal College of Psychiatry)

<http://www.suffolk-carers.co.uk> (Suffolk Carers)

**The information contained within  
this booklet is correct at the time of  
printing ~ Spring 2006.**



**This booklet has been produced by a group  
of interested people that comprise Service  
Users, Family Carers, Voluntary & Statutory  
organisations within Suffolk.**

**We are happy for this booklet to be  
reproduced, but please acknowledge its  
source.**

**Also available on Suffolk Carers Website  
[www.suffolk-carers.co.uk](http://www.suffolk-carers.co.uk)**