

# Carers guide to information sharing with mental health clinicians

Communicating for better outcomes

*“The task of lifetime care is continuous and who but the carers know the whole story.”*

(E: Carer, Perth WA)



This guide has been developed in partnership between the School of Psychiatry and Clinical Neuroscience, UWA; the Mental Health Division; the Office of the Chief Psychiatrist and Carers WA

## Introduction

This leaflet is for you and other family members and friends who provide ongoing care and support to a partner, relative or friend who has a mental illness. During the course of caring, you as a carer may face difficulties arising from the sometimes complex issues of confidentiality. Mental health clinicians were previously restricted in involving carers in discussions regarding treatment and care because of the consumer's right to privacy. However, it is now a requirement of law that carers are given information that is necessary for you in providing care. This guide describes some of the main problems you may have encountered and suggests ways others have dealt with them to achieve more positive results for everyone concerned.

*"...a diagnosis is made after a 15-20 minute appointment. We as parents have our child's life history."* (P: Carer, Perth WA)

**The Western Australian government**, in its *Report on the Review of the Mental Health Act 1996* recognises your rights as a carer and the information and support you need. For example, accepted recommendations include:

- 5.4 the Act be expanded to include the rights of carers and access to health care and support services for carers (1.4);
- 5.20 carers' involvement in treatment be expanded leading towards a partnership model of care (5.4A);
- 5.26 patients, carers and representatives be provided with information about their rights and entitlements (7.1);
- 5.4A a new section be added to the WA Act requiring patients capable of giving consent to be asked, upon hospital admission, about carer consultation.

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1 'Carer', as used in this document, refers to any family member, relative or friend who provides ongoing care and support for a person with a mental illness without payment other a pension or benefit.

**Minors:** Recommendations in the above Report allow for the concept of a competent minor:

- 5.39 the Act has a specific part for dealing with minors (Y);
- 5.40 the concept of the competent Minor be introduced into mental health legislation

### **Why is it important that appropriate information is shared between mental health clinicians and carers?**

*We need to understand what the triggers of a relapse are, and what the treatment will be, and get early intervention and quick responses: this stops the illness getting out of control. So if information is not shared with us, we won't know when to seek help. (M&B: Carers country WA)*

#### **History**

As a carer, you are often the one who knows the history and health of the consumer best. As well as generally having the most contact with the consumer, you usually have the most concern and responsibility for their ongoing welfare over many years. Research shows treatment works best when everyone shares their knowledge of what is happening and what is being done to help. That you and health clinicians share appropriate information is therefore essential for your and the consumer's ongoing wellbeing. Your views must be considered before any decisions regarding the consumer be made, to avoid risk of any untoward consequences for either the consumer or yourself.

*The carer is there 24 hours. I have the information about how certain drugs are working. I need information about the availability of other therapies i.e., cognitive therapy etc. (M: Carer Perth WA)*

#### **Feelings and Coping**

Being involved with health clinicians in discussions and decisions about the consumer's treatment and care can help you cope with

the feelings of grief, loss, isolation and aloneness commonly felt by carers. Caring is difficult and stressful. To cope with caring, you need to feel part of a supported team with ready access to up-to date information. Often, it is just as important that you know such information as it is that specialists and other health clinicians know it.

### **Planning for Emergencies**

Mental illnesses can cause sudden psychotic crises requiring your immediate response - often at night or outside working hours. This is highly stressful for you and your family when appropriate professional help is not readily available. It is therefore essential that managing these times has been previously planned for, at the earliest time when the consumer has stable health. Mental health clinicians should ensure that such planning is done as soon as possible, by asking for your and the consumer's involvement in developing a treatment, ongoing care, and crisis plan.

### **What You Need To Know**

It is important that you tell mental health clinicians the type of the information you need - when you need it:

*“Are the problems we discuss side effects of medication or of the condition?”*

*What can be done to help?*

*What support is available to us e.g., regarding motivation, weight loss, etc. (M: Carer Perth WA)*

Mentally ill consumers may lack the objectivity and insight necessary to give an accurate account of their health problems to health clinicians, particularly during an episode of health crisis or psychosis. At such times the information you as carer can provide is critical, as for example: ...”*when a patient is unwilling or unable to divulge information or does not realise the information he has may affect a different diagnosis”* (P, Carer Perth WA).

Often you are the only constant support in the consumer's life. Consumers regularly experience sudden changes in their care team with the high turnover of clinicians. As a result the building of trust and thorough knowledge of the consumer in these relationships is difficult. As a carer, you must be regularly included in discussions, to ensure that important information is not lost.

### What problems are involved in sharing information?

*What I find most difficult to deal with in getting the information I need is: having to repeat the story over and over to different people then staff trying to exclude me in times of crisis (K: Carer Perth WA)*

### Professional Codes of Conduct

In general health care, health providers, consumers and their families are increasingly viewed as partners in care. However, complex and sensitive situations arise in mental health care that create difficulties in information sharing.

Many different health clinicians may be involved in the long-term care of a consumer with a mental illness. Legal, ethical, and professional codes of conduct protecting the privacy of the consumer, have previously only allowed for relevant information to be shared among health clinicians as required for the treatment and care of an individual. However, recent legislation now makes it a requirement of law that health clinicians share with you information necessary for you in your role as carer.

Examples of problems that clinicians face in relation to information sharing include:

- **Legal and ethical obligations:** all health professionals are governed by law and professional and ethical codes of conduct to a duty of care and confidentiality to their patients. They also have a duty of confidentiality to carers. A clinician who breaches confidentiality is liable to disciplinary action, including dismissal and legal proceedings.

- **Consent to divulge information:** many carers are unaware that mental health clinicians must first seek the consumer's consent to share information with the carer. To the health clinicians, it is vital that such consent is obtained. Difficulties arise when the consumer is unable or refuses to give such 'informed consent', as for example when suffering from dementia or an acute episode of mental illness.

### Barriers for Carers

Carers also encounter serious problems with information sharing. For example:

- **Jargon:** ask the health clinicians to explain terminology and acronyms that you don't understand.
- **Time:** We are all busy people, but 5 minutes of good information can help to prevent or reduce future crises.
- **Confidentiality:** If the consumer requests that you are not to be informed of certain information, this is to be respected. However, any information which is essential for you in caring for and supporting the consumer must be shared with you.
- **Health deterioration risk signs:** Changes in the consumer's behaviour or sleep patterns may clearly signal deterioration of health and impending crisis. However, a consumer in such a state, not realising they are ill, may not want you to alert health clinicians. The consumer may consider such communication between you and the health clinicians to be a breach of trust. Such situations are best dealt with by anticipating and planning for their eventuality in discussions between you, health clinicians, and the consumer at a time of stable health.

- **Frequent changes in clinical staff:** when there are frequent changes in clinical personnel treating the consumer, you may have to communicate the same information repetitively at each change-over. Such frequent repetition, time pressured health clinicians, and the stressful effect of the consumer's illness on you and your family can all result in essential information not being communicated or considered at critical times.

## Good practice solutions to overcoming barriers

Although some progress has been made towards involving carers as 'partners in care', there are still many examples of carers not receiving necessary information. However, this is gradually changing with the introduction of procedure guidelines and training for health clinicians in compliance with the recent amendments to health policy and legislation.

In some areas, successful mental health teams effectively engage carers in information sharing during service delivery. Their experiences and success offer many examples of good practice. In all instances, endeavour is made by the health clinicians to discuss confidentiality with the consumer as soon as is possible when the consumer is not acutely ill. A consumer needs to understand the importance of their carer receiving the information necessary for on-going care and support.

Some common barriers to information sharing are listed below together with examples of good practice that overcome them.

### 1. What if the consumer does not give consent for the sharing of information?

The treating health clinicians must meet and discuss with you as soon as possible, the information that will be necessary for you in providing care. If the consumer does not give consent to the sharing of information, it must be agreed between you and the health clinicians that you be given only such essential information.

- **Good practice solution - Non-consent:** Health clinicians should ensure the consumer understands the importance of you being sufficiently informed. They should take the time to sensitively explore reasons why no consent or only partial consent is given, record such issues in the consumer's notes, and ensure that relevant follow up and review is carried out where necessary. You must be kept informed of information essential for you, and the medical notes must be regularly updated and reviewed so that all clinicians are aware of any changes or progress in regard to this.
- **Good practice solution - Prior consent:** Effective good practice among health clinicians includes planning with the consumer (at times of stabilised health) for future times of health crisis. Such planning allows the consumer to pre-plan with health clinicians and yourself what the consumer would like to happen at times when they are unwell. With such planning, prior consent for information sharing is given to apply at those times when the consumer is ill, irrational or psychotic, and liable to revoke consent previously given in a rational state.
- **Good practice solution - Non-consent in acute situations:** In such instances the provisions of the Guardianship Act and Amendments allows for someone other than the consumer to give consent on the consumer's behalf for necessary treatment and decisions where the consumer is unable to. In an acute situation, this does not require you to have lodged an application for guardianship.
- **Good practice solution - Sensitive information:** The clinicians must help consumers and carers differentiate between sensitive information that a consumer may wish to keep private from the carer (for example, sexuality), and information relating to the illness, treatment and care that the carer needs to know. By clearly explaining in such cases that the consumer's privacy regarding such sensitive information can and will be protected, the clinicians will clarify the issue and build trust between all three parties concerned.

## 2. What if the health clinician uses confidentiality as a reason for not communicating?

Mental health clinicians may not have received training on how to deal with your needs as a carer, in addition to those of the consumer, in difficult situations involving confidentiality. In such instances, a lack of confidence regarding correct procedure may result in a health clinician giving no information to you, and using confidentiality as the reason.

- **Good practice solution - Professional training is required:** Confidentiality must never prevent a health clinician from listening to you. Information regarding consumer consent should be clearly and prominently documented in the consumer's case notes. You must be informed and advised accordingly. Health clinicians must involve and engage with you as soon as possible in the development of treatment and care plans, and view you as an important source of information and feedback on medication effects and the consumer's individual preferences. It is your legal right as carer to be informed and given information that is vital to your provision of care.
- **Good practice solution - Mental health ethics training is required:** Health clinicians must consider issues of professional ethics and confidentiality in the context of duty of care to the consumer (an individual is not an island but part of a family and a community).

## 3. Time constraints

Health clinicians working under time constraints may be concerned that time spent with you, the carer, is less time they have available to spend with the consumer. However, infrequent, limited contact with you and your family when you are stressed and emotional during times of consumer health crisis, together with frequent changes in health personnel, can result in health clinicians having a false picture of the consumer and your true family situation.

- **Good practice solution - Time allocation:** The time health clinicians spend with carers is vital for achieving the best outcomes for everyone involved and the best treatment and care for the consumer. Such time must be factored in as a necessary part of the treatment and care plan. This prevents problems arising from lack of communication, and information sharing between health clinicians and carers which can have grave consequences.

### Other examples of good practice

- Health clinicians must always give the required information to you without using jargon and in a way that a non-medically trained person can readily understand.
- Mental health clinicians from all involved disciplines, together with consumer and carer representatives should meet in discussion and training sessions to explore concerns regarding confidentiality issues and to develop a common confidentiality policy. Such a policy should then be used to develop procedural guidelines to ensure daily good practice for all.
- A member of the care team may be designated as the most appropriate person to be ‘care co-ordinator’ to act as a readily available contact person and point of liaison between you and other professionals. Such a person must have the necessary training and skills to communicate with and support you in your role as carer.

### Carers’ confidence to communicate

You must ask questions when you need information. Don’t worry if you don’t feel confident at first - you will build confidence over time. However, if you continue to lack confidence to ask questions, discuss the reasons for this and what can be done to help you overcome it with the health clinicians you feel most confident talking to. Your role as carer is a vital one. It is important that health clinicians fulfil their duty of care by advising, supporting and assisting you. Sometimes they may rely on you to tell them what you need and how you want them to help.

Always remember to write down your questions and then write down the answers to your questions as you receive them, ensuring that you understand what is being said by the health clinicians. Some carers also find that keeping a diary of the consumers' behaviour can help to give a good picture of times of good health and unwell periods. Such a record may also be beneficial for the health clinicians to know.

The attached Good Communication Checklist can be used as a guide for both the clinicians and you to ensure that you are both confident of what questions can be asked and what information should be shared.

*...We all discuss strategies we have in place to keep things level, and it is an extremely friendly atmosphere. [The psychiatrist] also gets to know the family dynamics, and interaction, along with developing mutual trust between all parties. (A: Carer, Perth WA)*

**For further information regarding this guideline contact Carers WA.**

**The information in this Guide will be reviewed periodically and amended as required.**

## **Acknowledgement**

The Partners in Care, an initiative of the Royal College of Psychiatrists, and the Princess Royal Trust for Carers, London, are gratefully acknowledged for their information booklet: Carers and Confidentiality in Mental Health: Issues Involved in Information-Sharing: which has been adapted for this guide.

## Good communication checklist

As a carer, you should be able to access the following information. Other carers have found the information listed below has been beneficial for them.

### **Carers to ask for and be given general verbal and written information about:**

- The mental health illness and diagnosis
- What behaviours to expect and how to handle them
- Medication - alternatives, benefits and possible side effects
- Available local services for the consumer - both inpatient and community
- Available local services for the carer - government, private and community
- Local and national support groups

### **Carers are given:**

- Ongoing opportunities to ask questions, give feedback, and discuss concerns
- The opportunity to see a health clinicians on their own
- The right to confidentiality in communications with and to a clinician
- Positive feedback as a valued member of the care team
- Confidence to express their opinion and concerns
- Practical and emotional support
- An assessment of their own needs and written care plan when required

**Carers are given help in understanding:**

- The rights and responsibilities of consumers, carers, and mental health clinicians
- Any restrictions on sharing information requested by the consumer
- The aims of, and what is involved in, the consumer's treatment plan
- A written care and crisis plan and a recovery programme
- The roles of each health clinician involved in care of the consumer

**Carers are to communicate to mental health clinicians:**

- Any history of the consumer relevant to the mental health illness and diagnosis
- Personal characteristics of the consumer that may influence the choice of medication or treatment
- Ongoing benefits or side effects of medication or treatment on the consumer
- Problems they have in caring for the consumer and when they need help in practical problem solving
- If they would like training in cognitive behavioural therapy
- If they would like family therapy sessions

**Trust is essential in good care. Trust must be developed between health clinicians and carers. The different problems faced by each need to be understood before mutual respect and trust can grow.**

**Notes:**



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