

## **3.4 Carers and family experiences**

The Review heard clearly that there are areas of service where carers and families believe that considerable improvements need to be made. For some, an unhesitating opinion was that the system, by virtue of not providing adequate timely and preventive care, was a major contributing factor to the patient's suicide.

While the Review received a considerable weight of negative carer and family experiences, a number did describe receiving positive and supportive care.

The prominent theme for carers and families was a concern for the safety and wellbeing of the patient and a persistent sense of powerlessness within the system. They expressed a need for information about admissions, treatment, referrals and discharge/transfer plans.

Carers were concerned about the patient's illness and said they need education to understand the illness, treatments and the course of the disease. Training is needed to implement helpful interventions, to de-escalate symptoms and to support the patients' restorative pursuits. The carers also described their exhaustion and said that the burden of care sometimes affected their own mental wellbeing.

### **Access**

Carers and family members describe a system that will often respond only when dramatic circumstances prevail, and that the response is often not consistent with what they would have expected.

The patient and others can be endangered while waiting for emergency intervention. There are times when a patient's deterioration places not only the patient at risk of harm but also carers, family and others. For one family, the difficulty of accessing inpatient care led them to hide until the patient committed a crime and the magistrate ordered him to be assessed at the Frankland Centre (a forensic psychiatric hospital).

One mother explained to the Review that the Mental Health Emergency Response Line (MHERL) does not always respond in the way that she expected. She said they seem to listen to her but did not offer to assess her son or advise her about what to do.

Carers reported it was difficult to access mental health community services after hours and on weekends and even when community emergency response teams (CERTs) are available they do not always come, or cannot come soon enough. In these circumstances, patients and carers rely on the EDs of hospitals to gain access to mental health services and this is a very serious deficiency.

A mother expressed dismay at the delay in CERT's arrival time after she had made an urgent request. The CERT visited the son's home 48 hours after she had called and they contacted her to tell her the patient was not at home when they arrived. She expressed surprise that the team said they would not make any further attempts to locate her son despite her description of the urgency. In fact, her son had presented himself to a mental health hospital and had been admitted as an involuntary patient. The lack of assertive follow-up to an emergency call combined with the lack of communication from inpatient services to inform the CERT of the patient's whereabouts demonstrate system fragmentation.

In an illustrative case, the florid symptoms of a patient prevented him from being able to engage with reception staff at an ED. The result was that he could not provide details that would enable access to ED services. His father offered the required information but the administrative staff member insisted the patient must provide the information himself. The father's action, born out of his serious concern for his son's welfare, was to remain in the ED with his son. It was only when his son's behaviour attracted the attention of the security guard that he was brought into the treatment area in restraints.

A Council of Official Visitors' representative from Kalgoorlie described two recent occasions where patients who had sought assistance did not receive care until they had broken the law and were taken by police to the ED. The inability of mental health services to provide care when it was needed and sought led to untreated conditions with escalating symptoms.

A lack of after-hours mental health services in an ED seemed to contribute to a young mother's increasing distress at the lack of response to her presentation and request for help. It was not until she took particularly dramatic action placing her child at risk of harm on her third presentation that she received assessment.

A proprietor of a psychiatric hostel said difficulty in obtaining timely mental health care for a resident with deteriorating mental illness is a major concern. The patient required hospitalisation and was told to wait in the community until a bed became available. The resident's behaviour escalated out of control and led to harm to another person. The patient was arrested and ordered by the magistrate to be assessed at the Frankland Centre. An earlier response from the system could have avoided this, such as community visits and treatment commencement by a community mental health service.

Carers and patients provided the clear message that earlier intervention is essential to ameliorate the exacerbation of mental illness both in terms of responsiveness at early onset of symptoms and in the promotion of mental health. In children and young people, intervention programs to assess early in a child's life the possibility of the development of significant mental illness are to be encouraged and developed and it is a recommendation of this Review that this takes place in a timely fashion.

### **Communicating with carers at entry to the system**

Carers expressed their confusion at the array of entry points and the difficulty in navigating the mental health system. A common theme is carers feeling disenfranchised from involvement in care, at times feeling that they would not have been involved at all unless they had insisted. Family members recalled receiving minimal to no information about ongoing treatment plans, discharge care plans and resources such as respite services that could assist after hospitalisation. Carers are usually key supports for patients and they want to be involved and informed about the patient's admissions, treatment plans and discharge plans.

One carer explained that the inpatient mental health service where her son had been admitted did not involve the family. A mother explained that even though staff knew her by name, they have never contacted her to say that her son had been admitted or discharged from hospital. However, if she rang to ask if her son was a patient there they would tell her. Some carers had been contacted about the expected length of stay of patients at some inpatient services but little or no information was provided about ongoing treatment and discharge plans.

A carer suggestion that clinicians take carers into a quiet space to discuss patient care and discharge plans was prompted by experiences of clinicians speaking to the carer in open spaces with no privacy and with many interruptions.

Carers were also concerned about the way in which clinicians communicated with the carer and patients. Although there are many staff who are kind, clinicians' attitude toward the patient and family was often experienced as judgemental and the staff as not empathetic. Another carer perceived that the staff in a mental health inpatient unit did not interact with the patients very often. The mother told the Review she visited her daughter for long hours over many days where clinicians were often behind 'the glass' at the nurses' station. She said they rarely came out except 'to tell them [the patients] off or give them medication'.

A young carer believed that he did not always receive information about his parent's condition, and that he did not receive any training from the mental health facility about how to manage his father's psychiatric condition. He felt that he was rarely briefed on any mental illness issues, recovery or appointments made for his father. At times, the lack of information led to the young carer feeling frightened about providing care and neglected by the system.

There is an impact on carers when patients go on leave (with or without permission) and are transferred or discharged. Carers need to be informed. This expressed concern of carers was emphasised for family members who said their rights should be respected, particularly when the patient has a history of violence or other disruptive behaviours. Carers stated that the responsible clinician should always contact the carer and check that the carer is feeling safe and help them to resolve any issues.

The Review notes that amid the array of expressed concerns by carers they have also pointed out attempts to improve communication and involvement. For example, after experiencing confused communications resulting from a patient not listing very involved and supportive carers as his contacts, the carer became involved in a Patient and Carer Committee.

The work of this Committee led to changes in the Carer Form and the hospital's process of collecting information about carers in the patients' record. The improved recording of the patient's relationships with family and carers provided clear information for clinicians with a record of whom to share information. Importantly, family members and carers were confident that the staff would identify them as the patient's social network.

It is acknowledged that there are situations when informing the carer or parents is not in the best interest of the patient, and times when the patient explicitly requests the carer not be informed. These ethical conflicts need to be carefully considered by the clinicians in light of their duty of care to the patient and to the carer/s.

Noted at the National Mental Health Consumer and Carer Forum (2011) and apparent to this Review is that mental health services and clinicians struggle to reconcile seemingly conflicting requirements in relation to information-sharing and their role and obligations under the *Privacy Act 1988* (Cwlth) and the *Carer Recognition Act 2010* (Cwlth).

Clinicians expressed concern about maintaining patient's privacy and wishes when carers and family members approach them. They said they were torn between the conflicting guidance of professional duty of care, the Privacy Act, the Carer Recognition Act and mental health service policies. Clinicians explained that their duty to protect their patient's privacy and rights often overrode the decision to discuss care with family members and carers.

Schedule 1 of the Carer Recognition Act – the Statement for Australia’s Carers – obliges health services to recognise and respect the relationship between carers and the persons for whom they care (s 1.6) and consider carers as partners with other care providers in the provision of care, acknowledging the unique experience and knowledge of carers (s 1.7).

The intent is to involve carers in patients’ care and to support carers in their role (Carer Recognition Act s 1.10). The *Mental Health Act 1996* s 206 legislates ‘even when consumer permission is not given, carers are to be given sufficient knowledge to enable them to provide effective care’. The proposed Mental Health Bill 2011 does address this issue to some extent.

Many family members and carers acknowledged that the patient might not want their family involved or informed. However, patient’s privacy can be enforced at the same time as providing carers with necessary information and skills and this should be a principle of all mental health services (Mental Health Law Centre). At times, the nature of conflict between the rights of patients and the rights of family members will result in a best course of action being to use a patient advocate or legal representative to work with the patient to determine what information could be shared and with whom (Mental Health Law Centre).

In the event that carers are at risk, clinicians have a duty to provide necessary information. For example, they should notify a person whose physical wellbeing is in immediate danger. This duty overrides the duty of confidentiality (see also Office of the Chief Psychiatrist brochure: *Communicating with carers and families*) (OCP 2011a). Several carers described traumatic consequences where this information was not provided.

### **Carer concerns about the quality of mental health care**

Carers articulated concern about the amount of medication patients were prescribed as well as their side effects. A carer reflected that when her son’s medications were reviewed in Graylands hospital, his 77 tablets were reduced to 28 and his homicidal and suicidal thoughts subsided. Her son had experienced multiple admissions and, according to the carer, this was the only time he had received a pharmaceutical review. In another case described by a carer, the patient was on so much medication they could hardly walk and this level of drowsiness made it unsafe to drive or work let alone be left alone.

The admission of involuntary patients under the current Mental Health Act does not mean that the patient will be kept in a locked ward, and they can be admitted into a non-secure environment. There has been confusion about voluntary/involuntary and secure/insecure environments. The intent of good practice is to provide care in the least restrictive environment possible and, as treatment progresses, move from a secure ward to less restrictive areas, all the time remaining as an involuntary patient.

Carers expressed concern that patients assessed to be at risk of self-harm could leave the services without supervision.

Carers views of non-government organisation (NGO) care is exemplified by one mother who expressed concern that a mental health carer who was assisting her son in NGO accommodation seemed unaware of his treatment plan, resulting in an assumption that medication had ceased. The carer had not checked the patient treatment plan, nor had the plan been discussed with the treatment team, which would have revealed the importance of a continuing medication regime. Without appropriate medication, the patient’s condition deteriorated and a lengthy period of hospitalisation followed.

Within some public hospitals there are psychiatric consultation/liaison teams of mental health nurses and psychiatrists who provide consultation for patients in the general wards. Despite the presence of psychiatric liaison clinicians when individuals with mental illness are admitted for medical or surgical procedures in the general hospital, psychiatric assessment and care is not always provided.

One carer's mother was admitted for an elective surgical procedure at a general hospital. The carer explained his mother's escalating mental condition and treatment to the surgeon, to the anaesthetist pre-operatively and to staff on the ward at admission. The carer also alerted the CMHS who reviewed the patient before hospitalisation and planned to review the patient when she returned home.

The carer recalled that there was no specialist mental health interventions during the inpatient stay, even though symptoms of a deteriorating mental condition seemed very clear. In the carer's opinion, discharging to home was not safe or realistic because she lived alone, her thoughts were becoming more disordered, she had difficulty ambulating, and was unable to instil the required eye drops post-operatively. His mother died within two days of discharge, the cause unknown.

This example highlights the need for general hospital staff to acquire knowledge about a patient's mental illness and gain access to specialist mental health services. A psychiatric assessment and treatment plan were needed to stabilise the woman's symptoms and could have informed the discharge plan.

The inability of the health system to respond adequately in the above situation is in part due to the segregation of mental and physical health within the WA hospital system. With a mental illness prevalence at 20 per cent of the WA population, along with the fact that mental illness commonly presents as comorbid to physical illness, an ideal would be that all health care staff require a minimum level of knowledge about mental health. Clinicians in general hospitals should possess the skill to identify when symptoms of mental illness require specialist psychiatric assessment and consultation.

### **Discharge and information sharing**

A number of carers described positive experiences with discharge processes at mental health units. For example, one mother described being involved in her son's discharge plan by a collaborative approach when her son planned to move into her home after hospitalisation. The service undertook a gradual approach giving her son the opportunity to adjust to living in the community on a community treatment order (CTO) by coming home for longer and longer periods until he eventually stayed home. Even after the successful transfer into the community, that mother continued to communicate with the treatment team on a daily basis by email to let them know how her son was progressing.

However, many carers explained to the Review that they were not always notified about discharge plans, nor informed when patients were on leave (officially or unauthorised). For one carer, the unexpected return of her violent partner endangered her life. This carer had specifically asked the doctor at the inpatient service to notify her should her partner leave the facility because of his violence. When the carer had recovered from her injuries in hospital, the carer explained she had contacted the psychiatrist at the mental health hospital and asked why she had not been notified, and the doctor replied 'because I don't have to'.

A carer described a paternalistic process when given a predetermined discharge plan at a family meeting. The carer was told, ‘This is what we decided’ and despite reading the plan and pointing out a deficiency, the carer was told that there was no time to go through it all and that this document summary was their plan (ARAFMI). The carer expected to be consulted about the discharge plan and to assist in a discussion to develop an optimal plan for care at home rather than to receive a predefined plan. In another case, a carer said that her son had had more than 20 admissions to psychiatric hospitals, and she did not know there was such a thing as discharge planning meetings.

Carers reported to the Review a number of very complex and traumatic scenarios in which the system seemed to flounder, and from the carers’ perspective, the system has seriously failed the patient and their carers.

One distressed carer was very upset to be informed by the police that his son had committed suicide while an inpatient in a psychiatric hospital and could not understand why the hospital had not contacted him. The *Coroners Act 1996* requires police to notify the next of kin in situations such as this and this Review is recommending that discussion be undertaken with the Coroner to allow dual notification in such events.

Several families expressed concern that the patients were discharged too soon with outcomes of potential and actual harm. One father explained that his daughter had called him from a bus on her way home from hospital stating she felt unsafe. He had advised her return to the emergency department. However, the patient chose not to do this. She later took her own life.

One carer expressed her frustration with the mental health system in relation to a patient with a dual diagnosis of sporadic illicit substance abuse and psychosis. The mental illness has debilitated the patient’s self-care capacity and there had been numerous ED presentations and hospital admissions during the course of the illness. Over the years, numerous experiences included premature discharge from hospital with unsuccessful accommodation and follow-up care plans. The mental health system was considered as unable to meet the patient’s needs.

A father has sought assistance from every level of the mental health system for his son with a dual diagnosis of intellectual disability and mental illness. The father explained the interplay of symptoms of each condition. Given the high level of mental illness within the population (40% of 40,000) of intellectually disabled persons, he would like staff within Intellectual Disability Services to receive education about mental health and for intellectual disability to be part of the curriculum for clinicians. For example, mental health clinicians need to ensure transport is arranged to transfer the patient to their place of accommodation on discharge from hospital when they cannot manage this themselves. On more than one occasion, this father found his son sleeping rough, having been discharged without necessary assistance and being unable to manage to get himself home.

This population group of intellectual disability, cognitive impairment and associated mental illness results in a most distressing clinical picture and these patients require protection. There is a People with Exceptionally Complex Needs Program that targets dual and multiple diagnosis of mental illness such as acquired brain injury, intellectual disability and significant substance abuse who pose significant risk of harm to themselves and others. This program currently has nine places and is planning an expansion to 18.

Older parents of adult persons with mental illness expressed concern about continuing care provision as the carers themselves aged and became in need of support. One family explained they were keen to develop an advanced care plan so that their wishes could be known about the ongoing care of their child.

## **Rehabilitation**

Carers recognised the benefit of involving family and patients in planning and implementing recovery plans. They said that patients often need individually tailored care packages that allow time for them to regain the skills they have lost. However, some carers were concerned that the focus of care was more often treatment with medication than a socio-biological framework that included rehabilitation. During the 20 hospital admissions for one patient at various mental health hospitals, one carer explained that only one had offered rehabilitation.

Some carers explained they had been left to their own devices to find out about rehabilitation services in the community because mental health services did not routinely provide such information. For example, one mother explained she researched community services herself and organised in-home services, including a mental health worker who then assisted her child to enrol in TAFE.

One carer described the positive effects of her son's stay in the step-down facility at Hawthorne House for 4–5 months. In this facility, her son participated in rehabilitative programs that have enabled him to be more self-sufficient in his permanent accommodation in a psychiatric hostel.

In the community, it takes time for patients to engage and establish a trusting and therapeutic relationship with the case managers, yet patients' case managers are continually changing, mostly due to staff turnover. The high level of staff turnover was perceived to reduce the effectiveness of care in the community.

## **Post-hospital follow-up**

Follow-up is not always considered adequate. One carer explained that the 20-minute visit every two months provides little more than medication for her son. Although his medication appears to be controlling paranoid thought and homicidal ideation, the patient's behaviours are increasingly inappropriate. The carer has been informed to ring the police to intervene and no other supports have been offered to manage the patient's behaviour. Further, a carer explained that the community mental health service had told her they did not involve the family in care.

One young carer told the Review that he was well supported by the NGO community support services. However, other carers perceived that discharge occurred without follow-up support. One mother continues to support her adult child (who has a mental illness) financially since the child's entire income is required to meet the cost of her psychiatric hostel accommodation.

Family members said patients benefit from assessment and treatment at home when their condition deteriorates. With care from visiting mental health services, increased community services and family support many situations can sometimes be alleviated in a less disruptive manner to the patient's lifestyle than admission to a mental health hospital.

Carers are acutely aware of the complex and difficult interplay of a patient's mental illness within environments of family, social, financial, welfare, employment and general coping with day-to-day living. Often the hospital is in effect quarantining patients for a time from the stresses inherent when trying to live in the community. Transitioning from hospital care back to the community is multifaceted and should not simply be a medical process.

Homeless patients do not have any place to store their medication or an address to be visited for follow-up care. There are no community nurses or social workers on the street providing crises accommodation. To stay in a shelter, people require photographic identification or a passport; however, patients do not always have these when they are discharged from psychiatric hospitals.

One mother explained that she had been told by the triage worker at a community mental health service to call the police when her son's behaviour was out of control. The mother feared her son would be arrested. It was difficult for her to discern the role of police in her son's mental illness. Psychiatric community support services were not offered.

### **Carer education and skills training**

Carers' perspectives in respect of carer education and training included a clear assertion that successful management of psychiatric illness and associated issues is dependent upon the family and patient's understanding of the condition, its manifestations and impact.

Carers told the Review they want to know how to provide care for someone with mental illness, acknowledging that mental health education occurred for some carers but not all. However, carers' perceptions indicate that a predominant feature is that most carers only receive informal training and information from clinicians in the course of their care of the patient.

The importance of providing formal and informal education and informing carers about the support and training available to them should be routinely emphasised during the health professional's training and ongoing professional development.

On the principle that carers are considered partners in care with the mental health system, there should be continuous information available to be delivered to family and carers. Carers and patients need formal and informal training to obtain the knowledge and skills they need to manage mental illness and there are some very good carer training programs available. Carers need to be informed and enabled to attend the training programs they need.

In an examination of five deaths, the Deputy State Coroner concluded that mental health services should be responsible for the carer's wellbeing and acknowledged services are not necessarily resourced to extend care to carers, which undermined the ability of the mental health system to provide holistic care (Deputy State Coroner's Report 2008, p. 5).

The Deputy State Coroner proposed that mental health resources should target carer and patient education about mental illness and associated issues. Contact information for services that can be helpful to the patient and carer should form a part of the information routinely provided.

The Review notes that some education and training for carers is arranged in partnership between the social workers and carer advocacy services, such as ARAFMI or MIFWA, at some hospitals including Northam, the Alma Street Centre and Joondalup hospital. This training, however, is not uniform in the system.

The training sessions provide a forum for the carers to learn about mental illness and to manage its effects as well as an opportunity to meet the social worker and carer advocate staff. The social worker and staff can provide ongoing support to them and a forum where the carers' views are listened to and valued (Manager Counselling and Support, ARAFMI). The areas presented include:

- *Mental Health Act 1996* and guardianship and administration
- mental health and drugs and alcohol
- bipolar disorder: how families and friends might respond
- schizophrenia: how families and friends might respond
- the young and mental health issues.

In the Wheatbelt, MIFWA works with the community mental health service to provide carer education. Mental health is promoted through population health forums and community networks. ARAFMI also organise education workshops in Perth, Broome and Carnarvon on topics such as:

- partners in depression
- coping with difficult behaviours
- assertiveness skills and smiles (a young carers' program) (ARAFMI).

Community mental health services also work with NGOs and Home and Community Care (HACC) to provide education to services and carers about mental health.

Knowledge of the Carers Recognition Act is a requirement of employment in mental health services and forms part of employment agreements. At Rockingham's mental health service, a carer consultant on the staff encourages family and carer interaction with the mental health staff.

At Rockingham General hospital, a number of family meetings are held. At the first meeting, families are invited to provide collateral information, discuss the effects of the illness on them and to develop a family support plan; the second meeting focuses on discharge planning; and the third meeting is a carer support group. Carers' education is a regular feature of mental health services at Rockingham and Peel. Programs including Hearing Voices, Grow and sessions by ARAFMI are also encouraged. As stated previously, the Rockingham–Kwinana mental health service appears to be an example of an excellent model of care.

At Northam, carers are also encouraged to contact ARAFMI and MIFWA, especially if patients refuse to have their involvement in care. The carer advocacy services provide the carers with the training they need to support the patient. Carers are encouraged to voice their concerns to the mental health staff, and support and training are provided to identify and decrease the stressors that can trigger patients' conditions. The premise is that carers require enough education and information to be able to assist the patient when they are discharged.

*See Recommendation 1: Governance 1.5; Recommendation 3: Carers and families; and Recommendation 7: Acute issues and suicide prevention 7.9.*