

### 3.3 Patients' experiences

Listening to the stories of people's experience of the mental health system was a critical and informing aspect of this Review. This Review has heard about the system from the patient's point of view through face-to-face interviews, group forums and by written submission. In some cases, aspects and insights of a patient's perspective have been supplied by carers, family and advocates as they describe their lived experiences with the patient.

While the Review heard predominately from patients expressing serious concerns, a number of patients and their carers reported positive experiences, some recalling feeling comforted and listened to and some felt safe and secure when in care.

Patients were forthright in their expression of concerns about the system, pointing out flaws and failings.

The Review heard patients' descriptions of experiencing inconsistent responses of mental health services to their presentation, with assistance not available until they were at their most vulnerable and in crisis. For others, the difficulties of accessing services, long waits for assessment, little information about their psychiatric treatment or physical health, and scant rehabilitative services raises important questions that must be addressed by the mental health system.

#### Access and referral

Some parents with children suffering a mental illness explained to the Review that their children had presented numerous times to psychiatric triage and not been able to gain entry as expediently as they expected. Parents expressed anger and shock, and in the strongest terms said they felt that the system had failed to respond urgently to self-presentations at services and even with professional referrals.

A number of the stories presented to the Review were characterised by considerable trauma and, for some, sadly, suicide. In the following précis of patient stories, all were seeking validation of symptoms and to be provided with explanations of how the system could assist them.

- A GP's referral resulted in an appointment for a person at high risk in six weeks from the time of referral.
- A patient waited in the community for 48 hours to obtain a psychiatrist review.
- A patient was asked to wait on a bench at the Mental Health Triage for assessment; he waited there for hours that day, returned the following day and waited again.
- A patient was self-harming but not admitted to inpatient care.
- While waiting for assessment in the community, a patient's abnormal behaviour led to their assault while they waited for assistance in the community.

In each of these situations, parents expressed concern that the difficulty in accessing timely services was a major flaw in the system that contributed to the patients' suicides.

Delays receiving assistance culminated in some patients' behaviour escalating and WA Police intervening to de-escalate the situation and, in some cases, transport the patient to a mental health facility or ED for assessment. One mother described her son sitting on the bonnet of a police vehicle in the rain for an hour while he waited for a mental health service to assess him.

Parents explained that their child's physical health was attended to in EDs. However, in a number of cases their mental health was not assessed by a specialist mental health professional. A parent explained that her child had cut his wrists in the bath and was brought to the ED. In emergency, while the physical injuries were attended to, there was no psychiatric assessment. The Review suggests that the absence of psychiatric assessment in emergent situations such as this is a serious failing that must be addressed.

Conversely, this Review has formed a view that lack of attention to the patients' physical health when patients are under the care of a mental health service is an area that requires improvement in the system. Although many patients described receiving daily mental state examinations by nursing staff, they did not recall any type of physical examination at any time during their inpatient stay.

An insightful group of youth said that optimally there should be enough services to address everyone's needs and the system should be easy to navigate. They suggested that young people who were 'brave enough to go to their GP' with their mental illness concerns should be celebrated because health-seeking behaviour should be rewarded and early intervention in mental health is optimal.

A young person explained that she had presented to her GP at 17 years of age and explained her symptoms. The GP referred her to the triage team at a public mental health service. The triage staff asked 'a hundred million' questions and the patient was then seen by another worker (whose role was not identified to the patient) and who then made an appointment for her to return. The young woman returned to that appointment with her mother and after a brief assessment was informed that her illness was not severe enough to warrant mental health services. Instead, a letter was written to her GP and then she was to continue treatment with her GP.

This scenario continued with the same young woman presenting to her GP with depression and anxiety. Another referral was made to triage. On this presentation, she was taken to a consulting room and interviewed by a mental health worker (she was unsure of the discipline of the interviewer). She was informed that she was 'going through a phase', and needed to 'grow up' and she was again sent back to the care of her GP. She felt that her symptoms were not taken seriously. A more informed view by the mental health care worker may have validated her experience and provided insight into how she would be able to control her symptoms over time.

Her mental illness finally led to hospitalisation at a designated mental health adult facility where her condition was diagnosed. Now, after nine hospitalisations she is able to manage her condition and continue her educative pursuits.

Patients described a wish to be involved in decisions about information sharing and with whom it could be shared. A young person was concerned about information sharing with her parents. She said that when she presented to the GP with an eating disorder and self-harm behaviours, the GP had called her mother into the consulting room and exposed the marks of self-harm on the youth's legs. The forced and unexpected confrontation exacerbated the patient's distress. The dilemma of sharing information with carers is discussed more fully in Section 3.4.

## Admission to inpatient units

Patients' experience of admission to mental health hospitals varied. The circumstances of admission and voluntary or involuntary status appeared to the Review as important determinants in how mental health services were perceived.

One patient said explanations had been given about care and she felt involved in the development of her treatment plan. This patient's relationship with mental health staff in the inpatient setting continued after discharge and the patient confidently telephones these staff when she has troubled thoughts, especially at night. The patient told the Review that staff always respond to her and the interaction lessens her anxiety. Further, she explained that the psychiatrists have 'always listened' and 'worked hard' to modify medications and optimise her wellbeing.

By contrast, another patient described feeling very alone on admission. Some patients said they did not receive any orientation or explanations of care and treatment. One said she had wished there had been 'someone on her side' to explain the processes. She said that if someone was 'holding your hand' on admission it would ease the acceptance of help and encourage engagement with others. Instead, she was scared and perceived the service to lack a 'trusting therapeutic environment'.

Acknowledging that each patient's circumstance is unique, a common thread of feeling alone through an admission episode may be an important catalyst in considering patient advocacy and patient navigation from the point of admission. Every patient needs access to individual advocacy services to assist with navigation through the system and with the development of a care plan.

Lack of access to the treating psychiatrist concerned one patient, who described her referral to a public mental health unit from a private mental health hospital with a Form 1 (referral for assessment). This patient recalls that assessment by a psychiatrist was the only psychiatric interaction she received during her hospitalisation and she was never informed of her involuntary status.

Inconsistency in staff interaction with patients was described to the Review. For example, during one admission to hospital, nurses rarely interacted with one youth. However, during an admission to another hospital, the nurses were supportive of the same patient. Another patient found staff to be unsympathetic.

There was also inconsistency in involving the patient's family in care. A patient and carer wrote to the Review with concern that family and carers were not involved in her admission or plans for discharge.

Insufficient treatment information led to one patient feeling threatened. A patient explained that she had refused medications as an involuntary patient because the nurse would not describe what her medications were. The nurse told her she would be put in the 'quiet room' if she did not calm down. This patient absconded during a 30-minute period of unescorted leave by having her mother pick her up. Her mother later went to the hospital and negotiated voluntary status and the patient was discharged into her care.

Lack of clarity about voluntary and involuntary status and confusion about secure and insecure environments, along with patients neither receiving information nor understanding their status, should be afforded attention within mental health settings.

A patient cited her experience of being admitted to a designated bed in a public hospital describing how she had been refused leave and refused transfer to a private psychiatric hospital. Since the doors were locked, this patient assumed she was involuntary. However, when she retrieved her file through freedom of information, she found no forms that indicated she had been admitted with involuntary status.

Emphasised by a number of patients was that that admission to the mental health system can occur very abruptly, causing considerable disruption and distress that is exacerbated by not being able to sort out domestic issues.

In the crisis of admission, patients are often incapacitated or do not have the opportunity to prepare for a hospital admission. They often cannot carry out their responsibilities for childcare, pet care, payment for accommodation (rent or mortgage) and other bills and securing their employment and lifestyle (personal communication Dr S Patchett; and S. Boulter Mental Health Law Centre, 2012).

Where no family members are available or aware of admission, fulfilment of these day-to-day responsibilities of living does not occur, causing untold stress. There are occasions when the outcome includes recovered patients not having a home to return to when they are ready for discharge, or with home circumstances in considerable disarray.

This situation is made even more difficult when the patient is transferred long distances, such as from the Kimberley to Perth for treatment.

Often this occurs without notification to their family or the community mental health services. Many of these patients are Aboriginal people who arrive at inpatient facilities without winter clothing or money. Their families have difficulty finding out where they are because their official name is usually used by the hospitals whereas the families usually ask for the patient by their traditional name which is not recognised by the mental health facility.

When patients return, they can be taken to Perth Airport to wait all day for a flight, unaccompanied and without food. When patients arrive at their destination, they do not have money to telephone families to collect them, and many families are not notified of their impending discharge.

## **Rehabilitation**

Designing and effecting age-specific rehabilitation programs is highlighted as a needed improvement. One young patient reflected that during admission to a designated hospital bed, she had attended a mindfulness group. The other participants were adults and this presented difficulties as the issues seemed more suitable to an adult than to a youth.

In a group held with adolescents and youths on cognitive behaviour that the patient experienced at another hospital, the youth found the participants were at a similar developmental stage and this was beneficial to her understanding of her illness and its impacts.

Important benefits of skilled rehabilitation and counselling were characterised in the experience of working with a psychologist. The patient described how she was assisted to develop self-awareness and recognition of mood changes and how to respond, including how to contact the assistance of mental health care for support. This skill has given her a sense of control and she is more aware of when to seek help, and appreciates how her medications help to control symptoms.

When asked about rehabilitation, a number of patients explained they had never experienced any rehabilitation program. Instead, their treatment was focused on medication and they were left to their own devices to overcome self-care deficits and to motivate themselves with the encouragement of their family to become involved in educative and employment pursuits.

Patients explained that under the Medicare Better Outcomes Program, they can receive 12 psychology services or rehabilitation for three months. However, some need more sessions or time to benefit from treatment.

The Review formed the view that recovery and rehabilitation programs are areas in which concerted and careful attention should be directed. It is apparent that there are some areas of good practice. However, in general, recovery and rehabilitation is not a major focus of mental health care, with resources focused at intensive inpatient management.

### **Discharge and information sharing**

In direct contrast to many family and carers suggesting they were being given only minimal information, a number of patients described inappropriate information sharing and discussion with their families. For example, a young woman told the Review that she perceived hospital staff 'blamed her parents' for her overdosing. On discharge from an inpatient psychiatric unit, another youth explained that her father was informed that his child's self-harm behaviour was attention seeking. This minimised the youth's illness and the youth felt 'not believed'.

Youths claimed there should not be one golden standard for information sharing but rather each situation should be considered independently. Youths said they understood the importance of informing parents. However, in their maturing and seeking of independence, they did not always want their parents to know everything, and wanted a say in what and when information was disclosed. However, they recognised that information sharing is important when the illness is serious and ongoing.

Expanding on information sharing is an issue of patients' involvement in care and lack of explanation of treatment planning. For example, one youth said the medications were explained in a limited way and the pharmacist supplied written information. However, she was not informed that an electrocardiogram (ECG) was part of the process of care to monitor the effects of the antipsychotic medication on cardiac function. Being asked to have an ECG worried her.

Patients told the Review that the effect of ceasing medications was not always described to them. In the context of powerful medications, this is an area that can place patients at risk of harm. When one patient delayed filling her prescription until she had the money, she suffered severe symptoms associated with abrupt cessation of her medication. Other patients described how frightened they were when they experienced suicidal ideation and strange behaviour when they didn't take their medications and had not been warned about ceasing medication without advice.

One young woman explained how distressed she felt when she developed the side effects of metabolic syndrome. The unexpected alteration to her body exacerbated her sense of poor self-worth and led to increased social difficulties. She remarked that she was not told about this medication side effect and had not connected her treatment with changes to her physical appearance.

Exclusion from involvement in decisions about treatment and discharge plans was frequently described to the Review. Patients said they were told they were being discharged with little time to prepare their transport home and ensure they had food in the home or to understand medications and treatment plans and what to expect in follow-up. Late notice of discharge was especially difficult on weekends when community mental health services and GPs were not readily available.

## Follow-up

A patient explained that patients are often left to self-direct their care, and it would better to have a care coordinator with whom to discuss feelings and get assistance to navigate the system. Patients and families' perception that the system is complex is supported by the Review's observation that the system is complex and difficult to navigate. The patients consistently refer to a need for someone who could assist them to find their way or to navigate the system. This further emphasises the need for effective case management that extends through patients' transition from inpatient care and beyond into the community.

GPs are often referred to as the primary medical support for patients in the community and patients seemed aware of this. The health system and the mental health system may also be placing high and sometimes unrealistic expectations on the shoulders of GPs. By way of example, one young person explained she received no follow-up or instruction other than to go to her GP following a self-harm emergency presentation. The GP did not feel able to help her further because of the GP's own poor understanding of mental health conditions.

Some patients characterised GPs as 'lovely' and 'helpful with prescriptions' but that many GPs admitted to the patient that they are neither knowledgeable about psychiatric conditions nor confident to modify medication regimes. This type of open admission, combined with GPs referring to specialists when needed, was praised by patients. GPs were viewed as advocates who would persist in making referrals until their patient got the service they needed.

The role of the GP in the care of people with mental illness is discussed more fully in the GP section.

*See Recommendation 2: Patients; and Recommendation 7: Acute issues and suicide prevention.*