

## **APPENDIX A: Project Reference Group**

Ms Rosemary Warmington	Chief Executive Officer, Carers Australia SA
Dr Maria Tomasic	Psychiatrist
Ms June Mattner	Director of Clinical Services, Ramsay Health Care (SA) Mental health Services
Dr Sharon Lawn	Public sector service provider
Mr Anthony Fowke AM	National carer representative, MHCA Board
Ms Pat Sutton	Carer
Ms Ann Smith	Consumer
Ms Robyn Milthorpe	Australian Government Department of Health and Ageing
Ms Helen Schenscher	Public sector service provider (resigned 11 May, 2010)
Ms Janne McMahon OAM	Project Manager on behalf of the Network
Ms Judy Hardy	Project Officer

## **Standard 7. Carers**

**The MHS recognises, respects, values and supports the importance of carers to the wellbeing, treatment, and recovery of people with a mental illness.**

### **Criteria**

- 7.1** The MHS has clear policies and service delivery protocols to enable staff to effectively identify carers as soon as possible in all episodes of care, and this is recorded and prominently displayed within the consumer's health record.
- 7.2** The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.
- 7.3** In circumstances where a consumer refuses to nominate their carer(s), the MHS reviews this status at regular intervals during the episode of care in accordance with Commonwealth and state / territory jurisdictional and legislative requirements.
- 7.4** The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after engaging with the MHS.
- 7.5** The MHS considers the needs of carers in relation to Aboriginal and Torres Strait Islander (ATSI) persons, culturally and linguistically diverse (CALD) persons, religious / spiritual beliefs, gender, sexual orientation, physical and intellectual disability, age profile and socio-economic status.
- 7.6** The MHS considers the special needs of children and aged persons as carers and makes appropriate arrangements for their support.
- 7.7** The MHS has documented policies and procedures for clinical practice in accordance with Commonwealth, state / territory privacy legislation and guidelines that address the issue of sharing confidential information with carers.
- 7.8** The MHS ensures information regarding identified carers is accurately recorded in the consumer's health record and reviewed on a regular basis.
- 7.9** The MHS provides carers with non-personal information about the consumer's mental health condition, treatment, ongoing care and if applicable, rehabilitation.
- 7.10** The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record.

- 7.11** The MHS actively encourages routine identification of carers in the development of relapse prevention plans.
- 7.12** The MHS engages carers in discharge planning involving crisis management and continuing care prior to discharge from all episodes of care.
- 7.13** The MHS provides information about and facilitates access to services that maximise the wellbeing of carers.
- 7.14** The MHS actively seeks participation of carers in the policy development, planning, delivery and evaluation of services to optimise outcomes for consumers.
- 7.15** The MHS provides ongoing training and support to carers who participate in representational and advocacy roles.
- 7.16** The MHS provides training to staff to develop skills and competencies for working with carers.
- 7.17** The MHS has documented policies and procedures for working with carers.

## APPENDIX C: Focus Groups and consultations

CONSULTATIONS AND TELECONFERENCES	PARTICIPANTS	TOTAL
Melbourne Date: 17 <sup>th</sup> February, 2010 Chair: Ms Janne McMahon Facilitator: Ms. Judy Hardy	4 public sector carer consultants 1 private sector carer consultant 4 carers 2 public sector service providers 1 private sector service provider 7 NGO representatives (Peninsular Carers; Victorian Mental Health Carers Network; Grow; The Haven Foundation) 3 consumers	22
Adelaide Date: 22 <sup>nd</sup> February, 2010 Chair: Ms. Janne McMahon Facilitator: Ms Judy Hardy	7 carers public sector 4 carers private sector 1 consumer 1 public sector service provider 1 private sector service provider 1 NGO representative (Mental Illness Fellowship of Australia)	15
Brisbane Date: 1 March, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	3 carers public sector 3 carers private sector 2 public sector carer consultants 1 public sector consumer consultant 1 public sector consumer 1 private sector consumer 1 public sector service provider 3 private sector service providers 1 NGO representative (Carers Qld)	16
Launceston Date: 5 May, 2010 Chair and Facilitator: Ms Judy Hardy	4 Public sector service providers 2 NGO representatives (Carers Tasmania) 2 carers public sector 1 carer private sector	9
Brisbane Date: 2 March, 2010 Chair: Ms Janne McMahon Facilitator: Ms. Judy Hardy	5 public sector service providers – Queensland Health	5
Brisbane Date: 1 March, 2010 & 2 March General Practice	1 General Practitioner 1 Member Division of General Practice	2
Teleconference: NSW, ACT Date: 6 <sup>th</sup> April, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	2 carers public sector 3 private sector service providers 1 NGO Representative (ARAFMI)	6
Teleconference: NT, TAS, WA Date: 8 <sup>th</sup> April, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	4 carers public sector 3 public sector service providers 1 private sector service provider 3 NGO Representatives (AARAFMI, Carer Respite Centre)	11
Teleconference: NMHCCF, National Register Date: 8 <sup>th</sup> April, 2010 Chair: Ms Janne McMahon Facilitator: Ms Judy Hardy	3 carers public sector	3
Consultation: Austin Health Date: 17 February 2010 Chair: Ms Janne McMahon	1 Assoc. Prof. Richard Newton, Medical Director, Mental Health Clinical Service Unit North East Area Mental Health Service, Austin Health, 2 Dr. Raju Lakshmana, Clinical Director, North East Area Mental Health Service, Austin Health Director of ECT, Mental Health Clinical Service Unit, Austin Health 3 Rod Marsh, Senior Clinical Nurse, North East Area Mental Health Service, Austin Health	3
Key people consultations: Dr. Margaret Leggatt Dr Robert Menz Mr. Peter Gianfranco Dr. Aaron Groves Nick Goddard	Internationally renowned carer representative Senior Medical Advisor, Medicare Australia Director, MIND, Northern United Kingdom Director of Mental Health, Queensland State-wide & Mental Health Services, Tasmania	5
	Total participants	97

## APPENDIX D: Advance Directive for Treatment – Courtesy of

### HYSON GREEN CALVARY PRIVATE HOSPITAL

## ADVANCED DIRECTIVE

An advanced directive is an expression of the patient's preferences of future mental health care and treatment. The directive is usually written when the patient is well and referred to when the patient is experiencing a relapse in their mental health. Thus the patient is preemptively able to communicate their preferences for care.

This advanced directive should be filled out in collaboration with a clinician and is a summary of an agreement between the patient, psychiatrist, hospital and any other concerned mental health professional.

It should ideally be adhered to as much as possible with the understanding that clinical needs will at all times override any preferences expressed in this document.

The Advanced Directive contains information on the following:

- Signatories to the document
  - The treating team
  - Significant others to be contacted
  - Those **not** to be contacted
  - Early warning signs and symptoms and action plans
  - Preferred methods of transport to the facility
  - Preferred treatment facility
  - Preferred inpatient interventions
  - Preferred medication at each stage of relapse
  - Preferred treating psychiatrist/mental health professional/CATT etc
  - Preference to **not** be treated by psychiatrist/mental health professional
- etc

### Signatories to this document:

NAME	POSITION	CONTACT NUMBER
	Patient	
	Community Psychiatrist	
	Admitting Psychiatrist	
	GP	
	Community Mental Health Team	
	Partner	
	Parent	
	Friend	

**Preferred Treating Team:**

NAME	POSITION	CONTACT NUMBER
	Patient	
	Community Psychiatrist	
	Admitting Psychiatrist	
	GP	
	Community Mental Health Team	

**Significant others to be contacted:**

NAME	PHONE	RELATIONSHIP	SPECIAL TASKS	WHEN NOTIFIED

**Who NOT to contact/visit:**

NAME	RELATIONSHIP

**Relapse Prevention Plan:**

EARLY WARNING SIGNS	ACTION PLAN
<b>MILD</b>	
<b>MODERATE</b>	
<b>SEVERE</b>	

**Preferred transport to hospital:**

TYPE OF TRANSPORT	REASON
1	
2	
3	
4	

**Preferred treatment facility:**

FACILITY	REASON
<b>MILD:</b>	
<b>MODERATE:</b>	
<b>SEVERE:</b>	

**Inpatient interventions:**

INTERVENTION	REASON

**Other interventions:**

INTERVENTION	REASON

**Preferred Medication:**

MEDICATION	REASON

**Medications *NOT* to be administered:**

MEDICATION	REASON

**Preference to *NOT* be treated by Mental Health Professional:**

PROFESSIONAL	REASON

**NAME:** \_\_\_\_\_

**SIGNATURE:** \_\_\_\_\_

**DATE:** \_\_\_\_\_

## **The Ulysses Agreement**

The Ulysses Agreement is a non-legal document that serves as a proactive plan. It is named after the Greek mythological hero, Ulysses, who asked his crew to tie him to the mast of the ship so he could resist the call of the Sirens. It might also be referred to as a Care, Treatment and Personal Management Plan. It allows for a parent with a mental illness to prepare some information for sharing and to make some decisions in advance of going through a period of incapacitation due to their mental illness. The plan can outline provisions for themselves, their family and the care of their children.

There are several considerations in developing this kind of plan:

- *It is not a legal document.* As an informal plan, it depends on good faith and cannot be enforced through the courts. For example, if the parent states in the agreement that he or she does not wish to change it without a defined process, it is legally open to be changed by the parent at any time. Laws about child protection, custody and confidentiality supersede the agreement. Service providers should consult with their supervisors regarding their own ability to enter into advance plans.
- *It typically takes a long time to develop a plan that will actually work in a crisis.* The effectiveness of the plan corresponds to the strength of the family's support network. If this network is not strong enough, early efforts to develop a plan may still be helpful but the plan itself may not work out as hoped. For example, a preferred caregiver may not be endorsed by child welfare authorities (if they are involved with the family). However, it is likely that the relationship between the person named by the parent and possibly the child will be respectfully considered by those who work with the family.
- *The parent must be well enough to make a good, safe plan.* Some parents, especially people living in smaller communities, may be too isolated to be able to enlist others to give sufficient support. The nature of some mental illnesses (paranoia, for example) may interfere with the parent's ability to trust others even in developing a plan. Also, parents may not be aware of past histories of friends and acquaintances that would preclude them from being good caregivers for their children.
- *Children can have an active role in the plan, as developmentally appropriate.* For example, a child may be the first person to notice symptoms in their parent, and should have the means to seek help for themselves and their parent. An adolescent may have strong views about issues such as alternative care, which should be respected as far as possible.

## Basic Model of the Ulysses Agreement

A basic model of an advance plan for the care of children in the event of mental illness relapse should include the elements listed below.

- 1. Dates, Names, and Contact info:** List the people named in the agreement and their phone numbers. List the people to be informed about the agreement. The date is important because this agreement should be reviewed frequently as the information may change quickly.
- 2. Purpose:** The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by members of the support system if the parent exhibits symptoms of the illness which interfere with the parent's ability to provide good care for the child.
- 3. Symptoms:** List the symptoms that the parent making the agreement would like others to notice and respond to, and describe the most helpful way to respond. Often it is the children who first notice a worsening of symptoms in the parent and they need to know how to get help quickly.
- 4. Communication:** Record how the writer would like to deal with the issue of confidentiality, and attach signed consents if desired. Even with consent, no more information than is necessary for the implementation of the Agreement should be shared. The action plan can describe who the writer would like contacted, the order of response, as well as instructions about treatments or medications that have been helpful in the past.
- 5. Plan of Action:** Record the parent's wishes for support services.
- 6. Child Care Information:** Record the parent's wishes regarding the care of their child(ren), including any information about allergies, special needs, favourite foods or toys, daily routines, and so on.
- 7. Involvement of the Children:** Children can be a valuable resource to include in the agreement, where possible. They are often well aware of their parent's symptoms and, depending on their age, could be the first to get the Agreement plan into action when necessary. Involving children appropriately can increase their sense of security as well as their compliance with the Agreement.
- 8. Cancellation:** Describe the manner in which the Agreement can be cancelled. The purpose of the Agreement is so that it cannot be easily cancelled when the parent is actually ill, so it is wise to set up a process of cancellation that requires a period of time and a set of steps (note: this may pose a problem for some professionals who are unable to enter an agreement that does not allow for cancellation within a shorter specified time. It should be noted that this is an informal rather than a legally binding document, based on the good intentions to prevail, and wording to that effect may be included).
- 9. Periodic Review:** Describe the manner in which the Agreement will be reviewed (at least annually is recommended, as well as after each time the Agreement is put into action). At the review, a copy of the Agreement should be given to everyone named in it, and each person should be clear about his or her role. A meeting can be helpful to introduce the people in the support network to each other and to allow everyone to express their care, concern and support for the family.

**SAMPLE 1: Blank Ulysses Agreement and Addendum.**

**Ulysses Agreement**

Care, Treatment and Personal Management Plan for

\_\_\_\_\_  
Name  
Updated: \_\_\_\_\_  
Date

This is an agreement between the following people and myself, \_\_\_\_\_, of  
Name

\_\_\_\_\_  
Address

\_\_\_\_\_  
Phone

List names, addresses and phone numbers of those people involved:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Purpose:**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**My Symptoms (early symptoms):**

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Plan of Action:**

\_\_\_\_\_  
\_\_\_\_\_  
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\_\_\_\_\_  
\_\_\_\_\_





## **SAMPLE 2: Completed Ulysses Agreement**

The following is an example of a Ulysses Agreement that is constructed using the basic model. The Agreement was prepared with an actual family and used with success, but the names have been changed to protect confidentiality.

### **SAMPLE ULYSSES AGREEMENT**

#### **Care, Treatment and Personal Management Plan for Mary Grant Updated: April 3 2006**

This is an agreement between the following people and myself, Mary Grant, of 1234 64<sup>th</sup> Street NW, Prairieville, phone: 987-6543.

Mrs. Roberta Grant (Mary's mother)	403-555-6666
Dr. J. Addams (Family physician)	403-555-6543
Carol Noone (friend)	403-555-7777
Nancy Green (neighbor)	403-555-8888
Sue Linde (Midtown Mental Health Team)	403-555-4444
Dr. T. White (Midtown Mental Health Team)	403-555-4444
Dan Diamond (Alcohol and Drug Counselor)	403-555-3333
Cindy Fox (Social Worker)	403-555-2222
Fran Rite (Parent Education Worker)	403-555-1111
David Grant (son)	403-555-1234

The above have agreed to be members of my support team and to follow the guidelines set in this agreement, to the best of their ability. In addition, the Mental Health Emergency Services have been informed of my wishes as set below.

#### **Purpose:**

The purpose of this agreement is to provide a clear set of guidelines for actions to be taken by my support team if I exhibit any signs of my illness as outlined below. I appoint Roberta Grant, my mother, or in her absence Carol Noone, as overseers of this agreement to ensure that, as far as possible, it is completely implemented. The primary purpose of this agreement is to ensure that my son, Douglas, will be properly cared for with the least amount of disruption in his daily routine. My request is that support be given to my son and me so that I can continue to care for him at home. However, I understand that this may not be possible, and I trust that the people I have named will make good decisions, if necessary, for the care of my child if I experience a relapse of my illness.

#### **My Symptoms (early symptoms):**

- Difficulty falling asleep and staying asleep
- Increased irritability, anxiety and agitation
- Decrease in appetite
- Emotional withdrawal and social isolation
- Impaired judgment regarding money
- Intrusive, irrational thoughts
- Suicidal thoughts
- Hearing voices
- Increased generalized fear and anxiety

## **SAMPLE 2: Completed Ulysses Agreement (continued)**

### **Plan of Action**

Upon onset of the symptoms of my illness as detailed above, the following actions should be taken by my support team:

- There should be open communication between the members of my support team. Any one of my support team shall speak to me first about their concerns and then contact the Mental Health Team Case Manager.
- The following actions should then be taken:
  1. My mental health case manager, team doctor, myself, and any other members of my support team that I wish to be present, should meet for an assessment of my mental status. Adjustments in medication and a care plan should be established
  2. The team will provide increased support through more frequent contact and by advocating for additional needed services, such as homemaking
  3. The mental health case manager will contact the social worker to enlist her support and services. Specifically these supports would be a homemaker, increased child care and possible placement of my son if necessary
  4. The area counselor at the school should be informed of my difficulties so as to be responsive to possible difficulties my son may exhibit at school
  5. The mental health case manager will contact the friends I have listed to enlist their support
  6. If I am abusing substances the mental health team may contact my Alcohol & Drug counselor and elicit his support
  7. If I am unable to care for my son with the additional support, every effort should be made for my son to be able to remain at home under the care of one of my friends or relatives listed above
  8. Attached to this agreement is information important to my child's care
  9. Only after all efforts have been made to meet the above plans have been exhausted, will the case manager contact the Ministry of Child and Family Services to arrange respite care
  10. If after review and actions as outlined in #1 and #2 have not been effective in stabilizing me then I will give consent to admission to the Venture program. Arrangements for the care of my son are outlined below
  11. Hospitalization should be considered as a last resort

#### **Medication:**

As long as I remain stable, medications will continue to be dispensed to me on a monthly basis. Should I exhibit any symptoms of illness, this schedule will be reviewed.

#### **Medical Records:**

I authorize my case manager or doctor to discuss my mental status and current functioning or any other medical information required for decision making with any members of my support team, or any person responsible for my care.

## SAMPLE 2: Completed Ulysses Agreement (continued)

### Care for My Child:

In regard to my son Douglas, I would like the following to take place:

1. If I am not able to care for my son at home, or if I am admitted to Venture or the hospital, I request that Douglas be placed in the care of my mother, Roberta Grant. My mother will need to apply for compensation for the cost of caring for Douglas, and the financial compensation is contingent upon current legislation and policy. I request that Douglas' daily routine be maintained as closely as possible. This includes attending daycare on a regular basis. Please see the attached addendum for information about Douglas' routine and allergies
2. If my mother is unavailable immediately, I request that the Ministry make every attempt to place Douglas in her care as soon as possible. In the interim, Carol Noone or Nancy Green should be contacted regarding their ability to care for Douglas on an emergency short-term basis
3. If I have been admitted to the Venture program or to hospital, I agree not to have contact with Douglas for the first week of admission

### Cancellation:

As a result of my illness I might attempt to cancel this agreement. I only wish to cancel this agreement in the following way:

1. I will inform my case manager or doctor at the Mental Health Team that I want to revoke this agreement
2. My own team psychiatrist will assess me. The purpose of this assessment is to ensure that I am not showing symptoms of my illness. I would like another member of my support team to be present. The psychiatrist may consult with another doctor
3. The case manager and I will inform members of my support team of this revocation in writing

I expect this cancellation to take approximately two months. Until this process is complete, I want this agreement to remain in place.

### Addendum to the Ulysses Agreement Information re: Douglas Grant

Born: \_\_\_\_\_ Personal Health Number: \_\_\_\_\_

Family Doctor: \_\_\_\_\_

School: \_\_\_\_\_ 9:00 am to 3:00 pm. Phone: \_\_\_\_\_

After school care: \_\_\_\_\_

Contact person: \_\_\_\_\_ Telephone: \_\_\_\_\_

- Douglas is severely allergic to nut products. He is also allergic to dust, feathers, perfume and many other irritants. Caregivers must have an epi pen needle at all times. Douglas carries an inhaler for emergencies and uses *Ventolin* preventative

## SAMPLE 2: Completed Ulysses Agreement (continued)

medication three times per day. Please consult with his family doctor, who knows him very well, about any questions regarding his allergies or treatment.

- Douglas goes to bed at 8:00 pm with light out at 8:30 pm. He usually has stories and a light snack before bed. He brushes his teeth immediately after eating.
- Douglas has met several times with Barbara Bean, a family and child therapist with the Midtown Mental Health Team, who has helped him learn about my mental illness and express his feelings about how he has been affected by it. It may be helpful for Douglas to meet again with Barbara to receive more information and support.

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### ***Periodic Review of Agreement***

A review of this agreement shall take place every six months or as necessary. If this agreement has been put into action, then a review should take place as soon as possible after I am stabilized.

Signature of Mary Grant: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of all members of the support team:

	Signature	Date
1.	_____	_____
2.	_____	_____
3.	_____	_____
4.	_____	_____
5.	_____	_____