

Ulysses Agreements



For Families Affected by Parental Mental Illness

“The name Ulysses Agreement comes from the story of the Greek, Ulysses, who ordered the crew of his ship to lash him to its mast and disregard what he had to say, if he told them to steer the ship towards the rocky shore where voices were beckoning him”

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Mark Littlefield



A REASON TO HOPE. THE MEANS TO COPE.
BRITISH COLUMBIA SCHIZOPHRENIA SOCIETY



Littlefield & Associates

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http://www.healthservices.gov.bc.ca/mhd/pdf/supporting_families.pdf

Integrated Service Planning and Delivery

Advance Planning allows parents to informally partner with child welfare and community supports in order to ensure competent care even when they are ill.

1. Should there be consideration of the Advance Planning Process?

It is important for parents who have a mental illness with severe recurrent symptoms to make plans for the care of their children in case they suffer a relapse. When parents prepare an advance plan, their family, friends and community workers can come forward to help sooner, in alliance with the parent's wishes for the best possible care for their children.

Advance planning addresses both the needs of the children for ongoing care and the need for the parent to maintain a role in providing for care and continuity for their child. The process of developing the plan also helps the family develop a committed, responsive network of support.

An important feature of advance plans is to allow parents to communicate about their child's particular care needs. This minimizes disruption for the child, and ensures that allergies and medical needs, preferred toys and activities, usual routines and helpful relationships are maintained.

Developing an advance plan is therapeutic in itself, as the parent realistically faces the impact of his or her mental illness on the child, and takes steps to build a support network for the family. Parents who have made such a plan have been surprised at the positive response of friends or family when they asked them to make a commitment to help in the case of a future crisis. Friends, family and community workers often stand back when problems related to the illness are developing, wanting to help, but worried about going against the ill parent's wishes. Knowing in advance what role the parent would like them to take, gives people confidence that they are doing the right thing. Advance planning is also an important aspect of developing an Integrated Case Management Plan.

There are several considerations in developing this kind of plan:

- **An advance plan is not a legal agreement, unless made as an enhanced representation agreement under section 9 of the *Representation Agreement Act*. Such agreements, which are further discussed beginning on page 4, may include provisions for the temporary care, education, and financial support of one's minor children. In such cases, the person making the agreement must consult with a lawyer, and the agreement must be properly signed and witnessed.** An informal plan will depend upon good faith, and will not be enforceable through the courts. For example, even if the parent states in the agreement that he or she does not wish to change it without a defined process, it will remain 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 ability to enter into advance plans.

- If there is a Care Team in place the process can be accomplished quickly within one or two meetings. If on the other hand the team needs to be developed it could take more time. 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 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 illnesses (e.g. paranoia) 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 desirable caretakers of children

a) Care of Children

A basic model of an advance plan for the care of children in case of a parent's mental illness relapse should include the following elements:

Date and Support Team: List the date of the agreement and the people named in the agreement with their phone numbers. The date is important because this agreement should be frequently reviewed, as the information may change.

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 person making the agreement exhibits symptoms of the illness, which may interfere with the ability to provide necessary care to the children.

Symptoms: List the symptoms that the person 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 their parent, and they need to know how to get help quickly.

Communication: Record how the writer would like to deal with the issue of confidentiality, and attach a signed consent by the writer giving permission for various people on the contact list to share information with others. Even with consent, no more information than is necessary for the implementation of the agreement should be shared. The action plan can describe whom the writer would like to be contacted, the planned order of contact and response, as well as instructions about treatments or medications that have been helpful in the past.

Plan of Action: Record the actions the writer requests others to take, including provision of support services, for the implementation of this plan.

Childcare Information: Record the writer's wishes for the care of the child, including any information about allergies, special needs, favorite foods or toys, daily routines, etc.

Involve the Children: Children can be a valuable resource to include in the agreement. They are often well aware of their parent's symptoms and, depending on their age, could be the first to put the agreement into action when necessary. Involving children could increase their feeling of security as well as their compliance with the agreement.

Cancellation: Describe the manner in which the agreement can be cancelled. The agreement is written expressly so that it cannot be easily cancelled when the writer is acutely ill. It is important that the process of cancellation 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 agreement, based on good intentions, and wording to that effect should be included.)

Periodic Review: Describe the manner in which the agreement will be reviewed (at least annually, as well as after each time the agreement is used). During 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 in that people in the support network become familiar with each other and express their care, concern, and support for the family.

This kind of plan or agreement is not legally binding, and relies on the good intentions of the people named in it to carry out the parent's wishes. Note that legislation regarding child protection supersedes such agreements. Social Workers, in the Ministry of Children and Family Development, should consult with their supervisors regarding their ability to enter into advance plans.

b) Advance Planning: Representation Agreements

New adult guardianship legislation provides a legal format for advance planning. The *Representation Agreement Act* allows adults to authorize representatives to exercise particular powers agreed to in advance. For example, a representative will be able to arrange for the temporary care, education, and financial support of children, as described in an agreement made by a competent adult. A representation agreement will need to be drawn up by a lawyer if it includes such arrangements. Materials to help people develop representation agreements are available from the Representation Agreement Resource Centre, (Tel.: 604-408-7414) and e-mail: (info@rarc.ca). The Web site (www.rarc.ca) has a copy of the *Representation Agreement Act* and the regulations.

2. Is there an Integrated Case Management/Family-Centred Case Management or Care Team?

There are many models of integrated case management and we are going to talk about two of them:

- (i) The Ministry of Children and Family Development (MCFD) has developed a model of integrated case management and collaborative practice which promotes the use of case conferences and a team approach to the development of a treatment or care plan for the family. This model can be empowering for parents, and can often generate workable solutions for complex problems. Integrated case conferences can be used to develop plans to prevent future crisis situations, or to decide on the most helpful ways to support the family. It is very important for the parent or the parent's voice, as represented by a

trusted person or recorded in a care plan, to be included at integrated case conferences. Any member of the service providers, including the parent or older adolescent may fill the role of case manager. Any parent who is involved with the MCFD can request a case conference through the assigned worker.

A representation agreement is somewhat like Ulysses agreement, which is named after the Greek mythological hero who asked his crew to tie him to the mast of his ship so he could resist the call of the Sirens; it might also be called a Care, Treatment and Personal Management Plan.

Meetings are recorded and the resulting plan is distributed to all participants, which encourages accountability and follow-up. Face-to-face meetings allow for the clarification of roles, making sure that agreed-upon follow-up occurs. Meetings also allow for the generation of helpful ideas and the creation of a care team that works collaboratively with the family.

Training for communities in Integrated Case Management is available throughout British Columbia, through the Ministry of Children and Family Development. Excellent materials, including a user's guide, an instructor's manual and a participant's manual, are available on the MCFD Web site: http://www.mcf.gov.bc.ca/reports_publications.htm.

(ii) Family-Centred Case Management establishes that the parent or person delegated by the parent as case manager will coordinate regular meetings of all care providers. This approach helps everyone work collaboratively, reduces duplication of services and encourages teamwork while reinforcing the parent's role as co-coordinator of services for the family. Family-Centred Case Management is frequently used in situations where the family's complex needs do not include the MCFD services.

3. Considerations for Integrated Case Management/Family-Centred Case Management for families with parental mental illness:

- Is there identification of individual and family strengths and assets?
- Is there consideration and respect for issues around confidentiality for the person with a mental illness?
- Is there a mechanism for resolving problems and misunderstandings that can arise in case management?
- Is there a regular process for educating all members of integrated case management teams in how to deal with conflicts and concerns?
- Are family plans of care developed, as well as individual plans?
- Is there particular attention to understanding, inclusion, and empowerment of both the parent and the child or youth?

ADVANCE PLANNING – AN EXAMPLE

Care, Treatment and Personal Management Plan for Mary Grant

Updated April 3, 2001

This is an agreement between the following people and myself

(Mary Grant, 1234 W. 32nd St., Vancouver, Telephone (604) 555-8999):

AND

Mrs. R. Grant	(mother) 555-6666
Dr. John Adams	(family physician) 555-6123
Carol Noone	(friend) 555-7777
Nancy Green	(neighbour) 555- 6666
Sue Linde	(Midtown Mental Health Team) 555-8441
Diane Diamond	(Alcohol and Drug Counselor) 555-6789
Dr. T. White	(Midtown Mental Health Team) 555-8441
Cindy Fox	(Social Worker, MCFD) 555-4444
Fran Rite	(Parent Education Worker) 555-8888
David Grant	(family member) 555-2222

They have agreed to be members of my support team and to follow the guidelines set below, to the best of their ability. In addition, the Mental Health Emergency Services (Car 87) have been informed of my wishes as set **out 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 supervisors 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 interference 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 may not be possible, and I trust that the people I have named to make decisions, if necessary, for the care of my child if I experience a relapse of my illness.

My Symptoms (early symptoms):

- Difficulties 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

Sometimes waiting too long before seeking support for a parent with a mental illness may be harmful to the children involved.

Plan of Action

Upon onset of any of the symptoms of my illness as detailed above, my support team should take the following actions:

- There should be open communication between the members of my support team. Any member of my support team should speak to me first about his or her concerns, and then contact the Mental Health Team Case Manager.
- The main purpose of this Advance Plan is to ensure the safety and well-being of my son. If there is any concern that he is at-risk or is not being cared for safely, the matter should be reported directly to the MCFD.

In British Columbia and many other jurisdictions, every person who may be aware of unsafe circumstances in the life of a child has a legal duty to contact appropriate authorities.

- The following actions should then be taken:
 1. My mental health case manager, team doctor, myself, and any other member 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 will 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 MCFD worker to enlist her support and to obtain needed services. Specifically, these services would be a homemaker; increased childcare; and placement of my son if necessary.
4. The area counsellor 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 any substance, the mental health team may contact my Alcohol and Drug Counsellor and elicit her support.
7. If I am unable to care for my son with the additional support, it is my wish that every effort 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 and have been exhausted, the case manager will contact the Ministry of Children and Family Development 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 Venture. 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 agreement will be reviewed.

Medical Records

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

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 my child through the Ministry of Children and Family Development¹. I request

¹ Government support is contingent upon current legislation and policy in any given jurisdiction

that Douglas's 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 assertive attempts 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 hospital or Venture, I agree to have no contact with Douglas for the first week of admission.
4. Douglas knows that if I am unable to care for him, his grandmother will.

Cancellation

As a result of my illness, I might attempt to cancel this agreement. I wish to cancel this agreement only 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 any 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 Advance Plan

Information Re: Douglas Grant

- Born: _____
- Personal Health Number: _____
- Family Doctor: _____
- School: _____ 9:00 - 3:00 phone _____
- After school care: _____ phone & contact person: _____
- 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 Intal or Ventalin preventative three times per day. Please consult with his family doctor, who knows him well, about any questions regarding his allergies or treatment.
- Douglas goes to bed at 8:00 with lights out at 8:30. He usually has stories and a light snack (cereal) before bed. He brushes his teeth immediately after eating.
- Douglas has met several times with Barbara Bean, a family and child therapist at 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 provide him more information and support.

Periodic Review of Agreement

A review of this agreement will 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.

Signatures of all members of the support team should be obtained.

1) _____

Signature Date

2) _____

Signature Date

3) _____

Signature Date

If this document is completed according to the requirements of the *Representation Agreement Act* it can be an enforceable agreement.