

# SUPPLEMENTARY PAPER

## THE ULYSSES AGREEMENT

1 May 1992

*A Ulysses Agreement is an informal arrangement used by adults with a mental illness who experience episodes in which they are not capable of making certain decisions. The intent of such an agreement is to enable an adult to maintain a degree of control in his or her life during these episodes, to have their "well self" (which has better and more self-preserving judgement) take precedence over their unhealthier "ill self".*

*This agreement is named after Ulysses who, wanting to experience the sounds of the Sirens, tied himself to the mast and ordered his crew not to release him and to ignore any of his instructions to the contrary.*

*When the adult is capable of making decisions, he or she can arrange a Ulysses Agreement by convening a selection of friends, family members, mental health professionals, and any others in their social network whom they choose to enlist. Each participant in the agreement agrees to carry out specific responsibilities as outlined, and when possible to make specific decisions for the identified adult during the time he or she is unable to make capable decisions. A Ulysses agreement may (but not necessarily) include directives for medical treatment in the event of an acute crisis. These directives can function as both advance consent to certain treatments as well as advance refusal of others. Though these directives are not yet legally binding, they do issue a strong statement of the adult's wishes and informs those with potential legal and medical decision-making powers as to how the adult, in their most capable condition, would like the health crisis managed.*

*An important part of this concept is that all parties involved in the agreement are equally responsible to see that it is carried out as closely as possible in the event of a crisis. Therefore, it is not an instructive statement by the individual (such as a living will is), but rather an informal agreement between a group of people.*

**The Ulysses Agreement contains the adult's instructions on issues such as:**

**Activation and De-activation Criteria:** What are the specific signs, behaviors, and events which

activate the agreement? Who decides this? What happens when there is resistance to follow the agreement by the adult? What de-activates the agreement? Are there specific limitations of time period during which the individual can revoke the agreement?

**Treatment:** What treatment decisions does the adult specify to deal with the problematic condition which activated the agreement? What medical intervention is requested? Which are to be avoided?

**Communication:** Who is assigned to speak to the physician? Who needs to know if the adult becomes acutely ill? Who should liaise with whom?

**Childcare:** Who should take responsibility for the care of minor children so as to prevent neglect, danger, or the unnecessary intervention of social services?

**Finances:** Who will take responsibility for paying bills, doing the banking, paying the rent, etc.?

**Homecare:** Who will take responsibility for shelter needs, animals, plants, etc.?

**Work:** What steps can be taken to prevent consequences from the illness having an effect on job security? Who at work should know about the adult's illness?

### Who Can Benefit from a Ulysses Agreement?

*This kind of agreement is not suitable for everyone with a mental illness but can be of immense benefit for those whom it does suit. The adult embarking on a Ulysses agreement should:*

- *understand the illness and its consequences*
- *generally accept the diagnosis of a mental illness*
- *have insight into how the acute phase of the illness manifests for him or her*
- *be capable and willing to tolerate false alarms initiated by overly zealous or just plain concerned friends.*
- *have a support network which is generally stable, committed to the adult's well-being, and capable of following through on their part in the agreement.*

## AN EXAMPLE OF AN ULYSSES AGREEMENT

### CARE, TREATMENT & PERSONAL MANAGEMENT AGREEMENT

This is a agreement between David (Dave) Edward Beamish, of 555 Main Street, and the following people:

Dr. Tang, my psychiatrist, 555-8626  
Judith Langley, my mental health nurse, 555-8626  
Tekkie Smith, 555-3069  
Nancy Osprey 555-5287  
Carol Smith 555-8078  
Barbara Lynn, 555-1639  
Dr. Steve Hall, 555-1843  
Sam Tom my probation officer, (see CARE), 555-8834  
Kelly Williams 555-3273  
John Russ, 555-7626

These people are trusted friends or people who have experience with me and my illness. They have agreed to be members of my support team and to follow the guidelines set out below. The Vancouver and New Westminster police have been informed of my wishes as set out below.

#### PURPOSE:

The purpose of this Ulysses Agreement is to provide a clear set of guidelines for actions to be taken by members of my support team in the event that I exhibit signs or symptoms of mania or serious depression.

#### MY SYMPTOMS OF MANIA: The following are my symptoms of mania:

1. decreased sleeping with increased activity
2. excessive energy
3. grandiosity, inflated self-esteem, thinking I am better or more powerful than others
4. increased interest in activities, overspending, incurring heavy debts
5. extreme irritability, very demanding and angry when others do not jump to my commands
6. unpredictable emotional changes
7. talking more and faster than usual, shouting people down
8. thinking processes speeded up, jumping from one topic to another, racing thoughts, flight of ideas
9. denying that I have manic depression, refusing treatment, denying that I need lithium

Any four of the symptoms require action, as outlined below, to be taken.

#### PLAN OF ACTION FOR MANIA AND DIRECTIONS FOR POLICE INVOLVEMENT: For symptoms of mania the following action should be taken by members of my support team:

As many members of the team as possible shall consult each other and contact Nancy, as she has experience with my mania. If Nancy is not available, Steve should be contacted.

Nancy will alert Dr. Tang re what action is going to be taken as set out in this Ulysses Agreement.

Nancy will contact the Director of the Mental Health Centre.

The Director of the Mental Health Centre will contact the police and request that they pick me up for 72 hour observation in hospital, preferably the Royal Columbian Hospital.

If possible, any one of my support team or a worker from the mental health centre should go with the police to pick me up as I have experienced difficulty with the police in the past.

#### MY SYMPTOMS OF DEPRESSION: The following are my symptoms of depression:

1. feeling of uselessness, hopelessness, excessive guilt
2. slowed thinking, forgetfulness, difficulty in concentrating and in making decisions
3. not responding to the phone or to messages
4. too tired and weak to do anything
5. increase in appetite and weight
6. decreased sex drive
7. suicidal thoughts

Several of the symptoms require action, as outlined below, to be taken.

#### PLAN OF ACTION FOR DEPRESSION:

For symptoms of depression the following action should be taken by members of my support team:

As many members of the team will consult each other and contact Nancy.

If Nancy is not available, Steve should be contacted.

Nancy will alert Dr. Tang that action should be taken as set out in this Ulysses Agreement.

Dr. Tang will instruct a mental health nurse to go to my apartment at 555 Main Street to assess the situation. If there is a need for treatment I trust my psychiatrist to decide whether to treat me at home or in hospital. I usually do not need to be hospitalized when I am depressed.

I do not need the police to be involved if I am depressed.

**CARE:**

I will see my psychiatrist two times per week during any medication changes and have my lithium level checked weekly. Once the medication is stabilized I will see my psychiatrist one time per week and get my lithium level checked once a month.

The results of the blood test should be given to Dr. Tang, me, and my probation officer Sam Tom. The purpose of Sam Tom receiving the results of the lithium level is to ensure that the lithium levels are maintained, not to monitor the results of the lithium levels.

**MEDICAL RECORDS:**

I authorize the release of the following information to my support team or people responsible for my care: The attached medical history and medical information during which this agreement is activated

**TREATMENT WHILE IN HOSPITAL:**

I am allergic to chlorpromazine so while in hospital I SHOULD NOT BE GIVEN CHLORPROMAZINE under any circumstances. My normal course of treatment for mania is to take Haldol and to be re-established on Lithium. I am sensitive to Haldol.

Otherwise, I hereby authorize Dr. Tang to provide the treatment that he believes to be in my best interests even though I may at that time withhold my consent to such treatment or state that I do not want to be treated.

**FAMILY, HOME AND DISSEMINATION OF INFORMATION:**

My mother and step-father should be informed if I become hospitalized or leave town: Audrey and Frank Patrick, 555-4327.

If possible my rent should be paid to William Bander. It is \$245.

I would like Tekkie Smith or any other member of my support team to take care of my canary, Tucker, and my king snake, Holly.

**CANCELLATION:**

One of the outcomes of my illness is that I might try to cancel this Ulysses Agreement. I only want to cancel it in the following way:

I will inform Nancy that I want to revoke my Ulysses Agreement.

I will be assessed by my own psychiatrist, Dr. Tang. I will also be assessed by another psychiatrist. At both assessments a member of my support team will be present. The purpose of this assessment is to ensure that I am not showing any signs or symptoms of depression or mania.

My lithium level will be checked after I inform Nancy that I want to revoke and again one month later. The results of these lithium levels will go to Nancy. She may contact Dr. Tang about the results. The purpose of these lithium level checks is to ensure that my lithium level is in the therapeutic range.

Nancy and I will inform members of my support team of this cancellation in writing.

This Ulysses Agreement shall not be cancelled if my lithium level is not in the therapeutic range, or if either psychiatrist reports that I am showing any signs or symptoms of depression or mania. I expect this cancellation to take approximately two months and until this process is completed I want this agreement to remain in place.

**MY PROMISE NOT TO SUE:**

I promise not to sue any member of my support team who acts or does not act according to my instructions outlined in this agreement.

Signed, Sealed and Delivered

Notarized \_\_\_\_\_ Date \_\_\_\_\_ Signed by Dave Beamish \_\_\_\_\_ Date \_\_\_\_\_

Signatures of all members of my support team:

\_\_\_\_\_ ...

***The important features of the Ulysses Agreement are that:***

- *it reflects the expressed wishes of the adult,*
- *it allows the adult to choose the people who would support him or her in a crisis,*
- *it is limited to the times when the adult is not capable of making decisions,*
- *it greatly reduces the stress on both the adult and his or her friends and family,*
- *it reduces dependence on the formal service delivery system, and,*
- *it sets up a system where the adult can get treatment at a time when, because of illness, the adult is denying the need for such treatment.*
- *it can incorporate both advance consent and advance refusal*
- *it strengthens the cohesiveness of the support network*
- *it links formal (e.g. physicians) with informal (e.g. friends) individuals within the network*
- *it acts both to prevent crises and to manage them*
- *it currently is an informal agreement, so it is accessible to those who prefer to avoid legally binding agreements such as an enduring power-of-attorney.*

***Acknowledgments***

*We would like to acknowledge the work of Peter O'Loughlin who has long been interested and has furthered this concept.*

*We would like to thank Hugh McLellan for his sage legal advice.*

*And our deep appreciation to Dave Beamish who has shared his personal Ulysses Agreement with us.*

*We strongly recommend that adults have the right to plan for periods of incapacity. We urge service providers to facilitate the development of these plans. We recommend that this concept be incorporated into policy and practice in Mental Health Services.*

*The purpose of this Supplementary Paper is to facilitate informed discussion. We welcome your comments, suggestions and concerns. The Supplementary Papers are companion pieces to a May 1992 Discussion Paper, *How Can We Help?*, on self-determination, interdependence, substitute decision making and guardianship in B.C. Copies of the Discussion Paper are available for \$5 at the address below.*

**If you have comments or questions about this paper, please contact:**

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