

Mr & Mrs Brown  
1 Smith St  
Melbourne VIC

Dear Tom and Alice,

**RE: Rachel Brown           DOB: 01/01/2000**  
**1 Smith St, Melbourne Vic**  
**UR 0101010**

As discussed today in Clinic, this letter is to serve as a record of our conversations around Rachel's treatment.

As we discussed, Rachel has a condition called spinal muscular atrophy, which unfortunately is a progressive disorder of increasing weakness, including respiratory muscle weakness. There are no specific treatments available for this condition.

We have agreed that Rachel's quality of life is paramount in her care, and for these reasons, we need to detail what we could do in the event of cardiac and respiratory problems.

We have agreed that:

1. In the case of an infection, that we would treat Rachel with antibiotics, oxygen as is necessary and fluids and sustenance.
2. In the event of cardiac or respiratory arrest, that we would provide oxygen, stimulation and suction as required, but we would not proceed to invasive therapies including cardiac massage, drugs to restart her heart, or invasive ventilation, that is intubation.
3. At all times that we would be providing support and comfort for Rachel.

Would you be kind enough to read over this letter, and if you have any changes or alterations, please give me a call in the office so that we can make the amendments. If you are happy with this being a record of our discussions, I will enter the information on the hospital 'Treatment Plan for a Child with a Life-Limiting Condition'. A copy will be retained in Rachel's hospital record and another will be given to you to keep. If you have any questions, please do not hesitate to call.

All best wishes,

Yours sincerely,

Mr & Mrs Smith  
3 Victoria St  
Melbourne VIC

Dear Mr & Mrs Smith

**Re: Janet Smith – d.o.b. 01.01.01**  
**Melbourne, Vic**  
**UR: 0000002**

As discussed at our recent meeting I would like to formally put in writing our discussions. Would you be kind enough to read through the following plans and sign 1 copy of this letter, which will go into Janet's file and also one you can keep with you.

In our discussions we had all agreed that we want to do everything possible to keep Janet as healthy and comfortable as possible. However we agreed that her underlying condition, Batten's disease, is progressive and that there has been marked progression in her symptoms over the last few months. We agreed that we will continue to provide all sustenance, medications and oral antibiotics in the event of infections. We also agreed that other treatable things such as seizures should be optimally treated. However in the event of her heart stopping or her breathing stopping we understand that this could occur but we would not want her to be intubated (have a tube put down to her windpipe) and ventilated. We also felt that invasive treatment such as intravenous drugs to get her heart or breathing started should not be used.

We have agreed that in the event of her heart or breathing stopping that we would:

- a) Stimulate her
- b) Provide suction if available
- c) Provide oxygen if available
- d) We agreed that there will be no MET call, cardiopulmonary resuscitation or tracheal intubation.

If you agree to the above as being what we agreed I will record the information on our 'Treatment Plan for a Child with a Life-Limiting Condition'. A copy will be kept in Janet's notes and another will be given to you to keep.

If you have questions or further comments please do not hesitate to call.

All best wishes.  
Yours sincerely,

Mr & Mrs Miller  
1 Fitzroy St  
Melbourne VIC

Dear Mr & Mrs Miller,

**RE: James Miller – d.o.b01.01.01  
1 Fitzroy St, Melbourne  
UR 0000000**

I write detailing our conversation today regarding what we would do in the event of James having a cardio-pulmonary arrest (heart or breathing stopping). Also, this letter serves to put in writing discussions around the treatment for *reversible* conditions that are threatening James' life versus a situation where this is part of the progressive deterioration seen in Niemann-Pick type C disease.

James unfortunately has a progressive disorder called Niemann-Pick type C disease. This is associated with progressive deterioration neurologically and is ultimately fatal. As we all agreed, our aim is to preserve his quality of life, to treat James with dignity and to make sure that side effects from medications do not impact greatly on his quality of life. We all agree that we want to keep James as healthy and as comfortable as possible. However we agreed that due to his underlying condition there has been marked progression in his symptoms over the last few months. We will continue to provide all sustenance, medications and oral antibiotics in the event of infections and to treat his seizures.

In the event of James' heart stopping or his breathing stopping, we will look at each situation on a case-by-case basis. If the cause is reversible, most likely short-term and with treatment James will be able to return to his previous level of functioning and quality of life, then all treatment including resuscitation measures would be employed.

However if James' heart or breathing stopped and this was related to the underlying disease or if his quality of life was impacted greatly or if treatment would not bring him back to his previous level of functioning, then James would have:

- a) Suction (if available) with stimulation and oxygen (if available).
- b) A short period of bag and mask ventilation (if available) for a minimum of 1 minute. If there was no response then we would support him and make him comfortable.
- c) If James was in the hospital there would be no MET call, cardiopulmonary resuscitation or intubation or drugs to be administered other than medications to make him comfortable.

We also agreed that as James' quality of life changes then this plan will change.

If you agree I will enter this information on the hospital 'Treatment Plan for a Child with a Life-Limiting Condition'. A copy will be kept in his hospital notes and another given to you to keep.

All best wishes,  
Yours sincerely

Re: John X  
Address

D.O.B.: 17 January 1990 UR 0111111

**Care Plan regarding John X**

John has severe cerebral palsy (spastic quadriplegia), epilepsy, a gastrostomy tube, and a severe scoliosis. His condition is not curable.

Some important decisions regarding his future management have been made by his parents, Mary and Tim S, in conjunction with his paediatrician at the Royal Children's Hospital, Dinah Reddihough.

In the event of a deterioration in John's condition, the following treatment plan is suggested:

**The overall goal of John's care is to ensure his quality of life is the best it can be. Should he become acutely unwell, the focus of care should be on physical comfort, reassurance and support.**

It is most likely John will experience a severe respiratory illness. In this case he should receive the following treatment:

- Oxygen if necessary.
- Suction if necessary.
- Antibiotics if indicated.
- Fluids, either by gastrostomy or intravenously as deemed appropriate.
- CPAP\BiPAP on the ward.

He should not receive:

- Any form of ventilation.
- Cardiac compression.
- MET calls.

**The details of this plan have been documented on the 'Treatment Plan for a child with a Life-Limiting Condition' Form which can be found at the front of the current medical record.**

Should further information or discussion be required, please contact xxxx xxxxxxxxxx (9345 xxxx, pager xxxx), or if not available, the xxxxxxxxxxxxxx xxxxxxxx consultant on call.

Thank you for your care of John and his family.

Signed: ..... Mr Tim X

Signed: ..... Mrs Mary X

Kind regards  
Yours sincerely,