

Childhood Dementia Questionnaire

Australian Paediatric Surveillance Unit

Please return: (Using stamped addressed envelope) to –
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The Children's Hospital, P.O Box 34, Camperdown NSW 2050
Telephone: (02) 692-6548 Fax: (02) 692-6163

PAEDIATRICIAN

1. APSU Dr Code/Name: /.....
2. Address:.....
3. Telephone:.....
4. Fax:.....

PATIENT DETAILS

5. Patient's first name (first two letters):
6. Patient's family name (first two letters):
7. Patient's date of birth (day, month, year): / /
8. Post code of family:
9. Country of birth of child:

1. How sure are you that this child has lost previously acquired skills related to brain dysfunction

Circle the appropriate scale point:

| | |
Extremely Unsure Moderately Unsure Moderately Sure Extremely Sure

2. What was the appropriate length of time between onset of the symptoms and diagnosis ?

- a) < 3 months
- b) 3 months – 6 months
- c) > 6 months < 2 years
- d) 2 < 5 years
- e) 5 years and beyond
- f) Not known to me
- g) Information not available
(e.g. child institutionalised with little history available)
- h) Difficult to ascertain from the history

3. Does the child have a sibling or siblings affected ? Yes No Uncertain

If Yes, specify the age of sibling

4. Is the aetiology of the child's dementia known ? Yes No Uncertain

If Yes, what is the aetiology ? (See protocol for example)

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5. What clinical and diagnostic investigations are there to support this diagnosis ?

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6. If uncertain, what aetiologies are most likely and why ?

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7. What is the overall impact of the child's condition on the family's day to day functioning ?

Minimally impairing	Moderately impairing	Markedly impairing	Extremely impairing

8. Please indicate the impact on each of the following family members

	MINIMAL	MODERATE	MARKED	EXTREME
Mother	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Father	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Non-affected sibs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Grandparents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Marital Relationship	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Don't know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. How adequate are the current psychological support services for the needs of this child and the family ?

Very inadequate	Moderately inadequate	Moderately adequate	Very adequate

10. How much additional help at this time does the family require in the following areas ?

	MINIMAL	MODERATE	EXTREME
The physical care of the child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long term nursing care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Terminal hospice care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supportive counselling for parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supportive counselling for siblings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist Medical	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

In which of these areas is help most urgently required ?

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11. Would you be prepared to be contacted in 12 month's time for follow-up information ? Yes No

Thank you for filling out this questionnaire. Please contact if you have any difficulties completing it.