

UK Survey of Neuroblastoma families 2011

The purpose of this survey is to gather information from UK families on all aspects of dealing with a child with Neuroblastoma.

The aim of this survey is to assess the real situation faced by UK families with Neuroblastoma, and to highlight possible areas for further investigation and improvement.

The information gathered will be collated and all comments will be presented anonymously.

1. Parents name/s and contact details.
 2. Had you heard of Neuroblastoma prior to diagnosis?
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Initial Diagnosis

3. Child's name & Age at diagnosis.
4. How many visits to the GP and/or local hospital were made prior to diagnosis? Over how long?
5. What symptoms did you report?
6. Date of diagnosis
7. Cancer treatment centre
 - 7a. Consultant
8. Shared care hospital
9. Details of diagnosis
 - a) stage, MycN amp status
 - b) were you given this information and if so was it's significance fully explained to you?
 - c) further details such as bone marrow involvement, lymph node involvement, primary tumour site, Histology, etc
 - d) were you given this information? If so, how long do you think it took to fully understand the diagnosis?
10. What percentage of survival were you given at diagnosis?
11. What treatments have you had on the NHS?
12. What, if any, complications has your child suffered?

Please use this space to tell us anything else

Neuroblastoma in an infant

This section is for families who had a child diagnosed under the age of 2.

13. Were you told that your child had a 'much' better chance of surviving because of their age?

14. Did this influence your decisions at all?

15. Have you experienced a bar to services due to your child's age? If so, please give details.

Please use this space to tell us anything else.

NHS & supporting care

16. Do you feel confident that your child has/will receive the best treatment for them?

17. Do you feel you have a good relationship with your consultant?

18. Do you feel your shared care hospital provides a good level of care and expertise?

19. Do you feel there is consistency of care between your cancer centre and your shared care hospital?

20. Have you had access to a social worker while in hospital? If so, what has your experience been?

21. Have you had home support, from a community nurse or a charity or agency? If so, please give details.

22. Have you or your child/ren had any extra help and/or support in or out of hospital? If so, please give details.

23. What improvements, if any, would you like to see ?

Please use this space to tell us anything else

Off NHS treatments (including nutrition)

24. Have you researched integrated treatments, such as good nutrition?
25. Have sought the advice of a private dietician?
26. What dietary advice have you received in your cancer centre?
27. Have you gone against the advice of your NHS dietician? If so, what response did you receive?
28. Have you researched therapies available in this country, but not available on the NHS? If so, what?
29. Have you researched therapies not available in the UK? If so, what and where?
30. Have you asked your consultant about your child receiving these therapies?
31. What response did you get?
32. Has your child had any of these therapies? (please state which, where, and if possible, the costs involved).
33. Did you apply for PCT funding for this? What was the outcome?
34. What is your experience of these treatments? Is it positive or negative? What, if any, benefits do you believe your child has seen as a result?
35. What, if any, problems have you faced from your UK cancer centre/consultant as a result?
36. Do you feel reluctant to go against the advice of your UK cancer centre because your child needs or may need their help?
37. Do you feel that your UK consultant has given you all the information available, including treatments not available on the NHS?
38. Do you feel that your questions have been treated appropriately?

39. Do you feel you have been fully supported in your decisions?

40. Where do you believe you have obtained the best information from?

41. Were you told things 'off the record' by your UK cancer centre? If so, what? Include anything you were told that you would question now.

Please use this space to tell us anything else.

Refractory or 'Stubborn' Neuroblastoma

42. Has your child not fully responded to treatment? Please give details.

43. What follow up treatment has your child received?

43a. What, if any, treatment is planned?

44. Have you considered treatments abroad? If so, what and where?

45. Have you discussed this with your UK cancer centre? If so, what was their response?

46. Have you applied for PCT funding for further treatment? If so, please state which PCT. What was the outcome?

47. What follow up tests/scan regime is/did your child follow?

Please use this space to tell us anything else.

Remission

48. Is your child in remission? If so, how long have they been in remission?

49. What aftercare are you receiving? What is your scan/test follow up regime?

50. Has your child suffered any long term effects, either physically or emotionally?

Please use this space to tell us anything else.

Relapse (questions 50 and 51 are for relapse and non relapse children)

51. Has your child suffered a relapse? If so, please give details.

52. Do you feel you were/are suitably prepared for relapse? Were/are you aware of the percentages and the lack of a UK relapse protocol?

53. How was this relapse detected? Did your child have symptoms or was it found at a routine scan/test?

54. Where in treatment were you, or how long out of treatment were you?

55. What treatments, if any, were you offered?

56. What treatments did your child have?

57. Were you given any information about relapse protocols abroad? If so, what?

58. Did you ask your consultant about opting for a relapse protocol abroad?

59. What response did you receive?

60. Has your child had relapse therapy abroad? If so what and where?

61. What are your experiences of this? Are they positive or negative?

62. What problems have you faced from your UK cancer centre/consultant as a result of opting for these treatments?

63. Did your PCT fund these treatments?

64. Are you currently applying or appealing for funding from your PCT?

65. Have you paid for treatment privately? If you can, please give details of costs involved and how you have funded it.

66. What stresses have your family suffered due to having to seek treatment abroad?

Please use this space to tell us anything else.

Palliative care and Hospice

67. Did you meet the palliative care team prior to receiving a terminal diagnosis?

68. Have you visited or used a hospice during treatment? If so, please give details such as which hospice and what for.

69. Do you feel you were adequately supported during and after receiving a terminal diagnosis?

70. Where did you receive end of life care? Do you feel your child and your family received adequate support at this time? If so, from whom?

Please use this space to tell us anything else.

Bereavement

This section is for those families who have sadly lost their child to Neuroblastoma.

71. When did your child die?

72. What were the circumstances surrounding your child's death?

73. Do you feel your child could have had a different outcome if you had had more information and access to options available elsewhere?

74. Do you feel you were/have been supported by your UK cancer centre during and since your child's death?

75. Where do you feel you have had good support?

76. What advice would you give to families starting the journey now?

Please use this space to tell us anything else.

Family issues since diagnosis

77. Have you suffered depression after diagnosis?

78. Has your partner?

79. Has your child and/or their siblings?

80. Has this lead to problems such as cyclical mood swings, personality disorders, agoraphobia, suicidal thoughts?

81. Have you had support with this? If so, from where?

82. Has it affected your marriage? This could be positively or negatively.

83. Has your child's siblings been adversely affected? If so, please give details.
84. Do you feel you have had enough support from organisations and agencies?
85. Have you had a good support network through friends, family and/or your community?
86. Do you feel you and your child/ren have been supported well at school?
87. Has your child/ren had access to other support? If so, what and where?
88. How has your child's Grandparents coped with the diagnosis?
89. What family or individual support would you like to see from diagnosis through bereavement and beyond?
90. Have you suffered job loss and/or financial strain since diagnosis? If so, can you give details?
91. Have you lost friends or family to them being unable to deal with the diagnosis?
92. What thing/s do/did you struggle with the most?
93. How has Neuroblastoma had a negative impact on your life?
94. Do you feel your life has been impacted in any positive ways, such as new friendships, an appreciation of life, or something else?

Please use this space to tell us anything else

Government involvement

95. Is your local MP aware of your situation? If so, (and applicable) how have they helped?
96. Have you written to any government official or department regarding your child's diagnosis? If so, were you satisfied with the response? Please give details.

Causes of Neuroblastoma

While the causes of Neuroblastoma remain unknown, several questions have arisen with possible connections, such as UK cluster zones, where many children are diagnosed in close proximity to each other, or the possibility of drugs given prior to or during pregnancy for things such as fertility treatment, PCOS, or anticonvulsants.

For the purposes of this survey,

97. Do you believe a full survey should be conducted into these possible connections?

97a. Would you be happy to take part in such a survey in the future?

98. Is there anything in particular you would like to see asked?

Improvements for the future

99. What do you believe would make a positive impact on dealing with Neuroblastoma and overall outcomes in the future? This could be access to better information at diagnosis, access to treatments abroad, or greater awareness of Neuroblastoma and it's signs and symptoms to aid earlier diagnosis, or greater funding into Neuroblastoma research. Or something else.

100. What question/s would you like to see on this survey in the future?

Please use this space to tell us anything else at all

Please return this survey to contactfan@yahoo.co.uk or mail to
FAN The Old Stores, Main Road, Elm, Wisbech, PE14 0AB

Thankyou for participating

This survey is being conducted by Families Against Neuroblastoma reg no. 1135974