

Finding Asperger syndrome in the family
- a book of answers

Introduction

Four years ago we came away from receiving a diagnosis of Asperger syndrome (AS) for our son, Sam, with our heads reeling with questions. Some of those questions are here. In the intervening years I have talked to many people, particularly to parents newly facing a diagnosis (sometimes in a daughter, although more often in a son) and so other of these questions come from a kind of combined Asperger Child who emerges from us all.

One of those parents explained to me that part of her confusion came from the fact that she no longer felt that she knew her child. The experts who had given the label had, by doing so, seemed to understand her child's behaviour better than she did. The time from his birth until that point seemed to have been spent with one child; now she must let that person go and get to know this new, 'Asperger' child. This redrawing of the family map can be a difficult and painful process, and is one which is filled with questions. This book is for everyone coming to terms with that time. I hope it helps.

It is not a book which will give you bio-medical explanations for the ways your child's brain functions differently (there are plenty of those available already, if you can understand them!). What it will do is give you some insights into possible reasons why he behaves as he

does, and some practical hints as to ways to help him, and the rest of the family, move on into the future with AS.

You may have spotted that the three 'big' questions ('Will he get better?' 'How did she get it?' 'How bad is it?') are at the end of the book. This is deliberate. I think it is easy to feel, when you first face this diagnosis, that these are the *only* questions. In fact, as time goes on they become less urgent as the enormity of the diagnosis becomes less overwhelming. Instead you begin to realise that the other questions- about understanding behaviour, about ways to help your child and about learning to live with Asperger syndrome in your family - are just as, if not more, important. The big three are still there; go straight to the end and read them if you like - but don't discount all the other 'little' questions. Some of these may never have occurred to you before. Some may be things you were wondering about long before an official diagnosis. They are questions which occur at the level where it is easiest to understand and to help your child. Perhaps they are not so small after all.

A note:

This book is about having Asperger syndrome, so why does it keep going on about autism? There has been a lively (and as yet inconclusive) debate in academic circles of recent years: Is Asperger syndrome the same as autism? Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC) are terms designed to cover a full range of conditions, usually (although not always) including Asperger syndrome. I use the term 'autism' frequently in this book quite deliberately. For the first

year after Sam was diagnosed we used to tie ourselves into knots trying to avoid it - but in the end, it's only a word. Like 'Asperger', the more you say it, the less fearful it feels. My advice would be to say both ten times before breakfast; go to the bottom of the garden and shout them. Neither of them can hurt you if you don't let them!

Finding Asperger syndrome in the family: a book of answers

	Pages
.....	
Section One:	19
.....	
“Why does he do that?” Understanding your child’s Asperger behaviour	
1. Why does he make so much fuss?	19
2. Why doesn’t he make <i>any</i> fuss?	20
3. Why does he go on and on about things?	20
4. Why doesn’t she look at me?	21
5. Why does she still wet herself?	22
6. Why can’t he write?	23
7. Why doesn’t she smile?	23
8. Why does he read so much?	24
9. Why is he such a messy eater?	25
10. Why doesn’t he tell us what happened?	23
11. Why does it take her so long to answer a question?	26
12. Why does she sometimes appear to be deaf?	27
13. Why can’t he sit still?	28
14. Why does he call out in assembly?	29
15. Why does he hate having his hair cut?	30
16. Why can’t she follow instructions?	31
17. Why does he roar like a tiger when he’s angry?	31
18. Why is he so ‘into’ superheroes?	32
19. Why won’t he let me give him a hug?	33
20. Why does she push into queues?	33
21. Why does he bump into people?	34
22. Why doesn’t he sleep much at night?	34

23. Why does she talk in a funny voice?	35
24. Why does he say rude things?	36
25. Why does he keep losing things?	37
26. Why does he always behave badly when we go shopping?	38
27. Why does she like watching the same thing over and over again on DVD?	38
28. Why didn't she wish me Happy Birthday?	39
29. Why does she like sleeping in a sleeping bag?	40
30. Why is he frightened of stupid things?	41
31. Why does she talk to strangers on the underground?	41
32. Why does he have to spoil every big event?	42
33. Why does he cover his ears when he's frightened?	43
34. Why isn't he brilliant at maths?	44
35. Why does he go off by himself?	45

.....
Section Two **44**

.....
What next: What can we do to help?

36. Why do we always have to make plans?	46
37. Why were we told to get him a gym ball?	46
38. Why buy her a trampoline?	47
39. Should we give in to routines?	48
40. Why take him to a Speech and Language Therapist?	48
41. Why do we keep playing board games?	50
42. Why write her notes?	50
43. What are 'angry cards'?	51
44. How can I stop him from lashing out?	52

45. Why does our whole family seem to be ruled by the clock?	54
46. What should I tell her to do if she gets lost?	54
47. Should we insist, even if she gets upset?	56
48. Is it okay to keep on holding his hand?	57
49. How can we help him make friends?	58
50. Should we find him friends with Asperger syndrome?	61
51. Should we go along with his current 'Special Interest'?	62
52. How much computer time should we allow?	63
53. Which sports should we encourage him to play?	64
54. How do I prepare her for puberty?	65
55. What happens if we have to move house?	66
56. Should we change our diet?	68
57. What about vitamins?	69
58. Should we let her do the same things as other kids her age?	70
59. Should I teach him to swim?	71
60. What should we do if she's bullied at school?	72
61. How do we explain sexual dangers?	73
62. Should we explain if she appears rude to strangers?	74
63. How do we get him to the dentist?	74
64. How do we deal with obsessions?	75
65. How do I stop him from getting into trouble?	77
66. How do I get him to understand about personal space?	78
67. Should I let her wear whatever she wants?	79
68. What about the dangers of drink and drugs?	80
69. How can I encourage personal hygiene?	81

.....
Section Three **83**
.....

What about the rest of us?

Living with AS in the family.

70	Does that mean he'll never love us?	83
71	Do I really have to bother about all this when my son has AS so mildly?	84
72	If he's so clever, why is he doing so badly at school?	87
73	Why did she have to see all those specialists?	88
74	Are there any books on the subject I should encourage him to read?	89
75	What difference does a label make?	90
76	Is he Gifted and Talented?	91
77	Is he dyslexic?	91
78	Why is it that many of the symptoms I read about, I don't find in my son (who has the diagnosis), but in my neuro-typical daughter?	92
79	Does he know he's got Asperger syndrome?	93
80	Should we tell Grandma and Granddad?	94
81	What should we tell our friends?	95
82	Will she have to go to a special school?	96
83	Is he cleverer than our other children?	96
84	How do we stop our other children feeling left out?	97
85	Will he ever have a girlfriend?	98
86	When will he learn that we're joking?	98
87	What can we do all together as a family?	99
88	Does he have an imagination?	100
89	Does he have to go to school?	101

90	Doesn't he care when I cry?	102
91	Wasn't he sad when Granny died?	103
92	Doesn't he care what he looks like?	104
93	Could moving abroad be the answer?	105
94	Is he entitled to any benefits?	105
95	Will he get to university?	106
96	Has she got any special talents?	107
97	Should we forget about Christmas?	108
.....		
Section Four: The big Three		110
.....		
98	Will he get better?	110
99	How did she get it?	114
100	How bad is it?	116
 ...and Section Five		119
101	Why can't I have Asperger syndrome?	119
 <u>Useful-contacts-and-further-information</u>		