

# Epilepsy—giving the diagnosis. A survey of British paediatric neurologists<sup>☆</sup>

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Adult-centred studies continue to show poor information provision and understanding in people with epilepsy. This study explores whether paediatric neurologists work within a consultation framework designed to meet information needs. A questionnaire on how to give the diagnosis was sent to 32 UK Paediatric Neurologists. Consultation content was largely determined intuitively rather than on a shared knowledge of the process involved. Little consensus was identified in relation to analogy and the usefulness or awareness of available unevaluated literature; but most acknowledged the value of a specialist epilepsy nurse. Most responses were based on a typical medical agenda but less than 20% addressed emotional responses and adaptation. Three approaches were identified—'pro-active' (running the risk of overload but recognising the right of parents to information), 'reactive' (more individually tailored, but assumes doctors can judge parental reactions) and 'drip-feed' (protective and pre-selecting topics to meet the situation).

Our aim to establish a guideline proved impossible. Further study should develop more detailed models of the disclosure process, and identify epilepsy explanations that can be consumer-tested.

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*Key words:* epilepsy; diagnosis; family practice; disclosure process.

## INTRODUCTION

Giving the diagnosis of disability in a child to parents is a difficult and complex task that few relish. Done well it can reduce parental dissatisfaction and anguish; it can establish positive and important parent–professional relationships at a crucial time. Few models of good practice have been evaluated in terms of outcome. Cunningham *et al.*<sup>1</sup>, did find significantly reduced parental dissatisfaction compared to controls but this was limited to a small number of families with infants with Down syndrome. The generalisation of such guidelines to other conditions, particularly those that emerge slowly and are more diverse, e.g. epilepsy and cerebral palsy, is not advisable without further evaluation (Cottrell and Summers<sup>2</sup>, McKinlay<sup>3</sup>). Unmet information needs around the

point of diagnosis are still being reported for families of children with epilepsy (e.g. Laybourn and Hill<sup>4</sup>, Cunningham and Newton<sup>5</sup>) and for young children with epilepsy (Houston *et al.*<sup>6</sup>).

Multifactorial studies with parents of children with severe physical and learning disabilities have reported that the affective domain—the doctor's style and conveyance of warmth and understanding—and the cognitive/information domain, accounted for most of the variance related to parental satisfaction (Sloper and Tuner<sup>7</sup>; Quine and Rutter<sup>8</sup>). In their review of the needs of families with a child with epilepsy, Laybourn and Hill<sup>4</sup>, conclude that all require clear information and advice and the opportunity for unhurried discussion with a sympathetic medical advisor at the point of diagnosis. The affective aspect clearly relates to doctors attitudes, communication and interpersonal

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skills and even their personalities, and is generalisable across conditions. Some of this may relate to their self-confidence associated with the condition and how to disclose specific diagnoses. The information aspect—the content of the interviews and the order of providing information—is mainly specific to the condition and has received little attention.

The range of different experiences described by families of the disclosure process, even when the child's condition and family circumstances are similar, highlights considerable variance amongst professionals in their disclosure procedures (Turner and Sloper<sup>9</sup>). The response to such variance is to use individual improvisation, the justification being that more formalised protocols are not possible due to the high level of variance related to the conditions, the families and the context. However, it may also be due to a lack of an agreed set of principles and information, which inform training and practice.

Professionals increasingly wish to complement what is said in consultations with supportive information packages such as leaflets, books, and videos, yet few of those available have had any formal evaluation. This point was emphasised in Kenny *et al.*'s<sup>10</sup> review of patient information leaflets in family practice.

Studies to date have identified poor information provision but the focus has been on adults. A sizeable proportion of adults attending for hospital or general practitioner care reported they had received insufficient information about epilepsy in both settings (Buck *et al.*<sup>11</sup>). More recently Poole *et al.*<sup>12</sup>, in a questionnaire study of 2394 adults with epilepsy, found satisfaction to be high but information provision poor. Long *et al.*<sup>13</sup>, also found a poor knowledge base in 220 adult patients with epilepsy. Reflecting current practice fewer than half of the adults newly diagnosed as having epilepsy participating in a study on how to meet information needs reported having been given enough advice in epilepsy (Ridsdale *et al.*<sup>14</sup>) and that compared to doctors, nurses were highly rated in terms of giving clear explanations.

An audit conducted by Appleton *et al.*<sup>15</sup> looked at the management of 50 children. Communication was again identified as the weakest in clinical practice and fewer than 50% of the families involved were recorded to have been put in touch with a voluntary epilepsy organisation. No study to date has looked at the conceptual constructs that paediatric neurologists bring to consultations, or to what extent content is planned.

Our aim was to review current practice on how the parents of children with epilepsy are given the diagnosis, and try to identify a consensus of good practice to develop guidelines. We felt the current lack of information prevented the development of an 'ideal approach' which could be evaluated. We decided to use a descriptive and qualitative approach.

## METHOD

We sought the views of consultant paediatric neurologists currently practising in the UK. Although much of the regional centre work of paediatric neurologists in the UK is tertiary, most will have weekly experience, particularly in the home-based clinics, of giving families the news that their child has epilepsy. As they were based throughout the UK and this was an initial exploratory study, it was decided to use a questionnaire.

### Developing the questionnaire

Three paediatric neurologists described, as fully as possible, how they disclosed the diagnosis of epilepsy. All three had been actively engaged, clinically and academically, in the issues of disclosure for several years. The context was the consultation when the consultant told parents of a diagnosis of epilepsy in their child (up to mid-teenage years). In this respect they were to assume 'within existing resources' and based on a consultation lasting 30 minutes or so. Whereas this approach resulted in an idealised statement of practice intent rather than capturing what the neurologists actually did, it did allow insight into the conceptual constructs that these doctors took into each consultation.

Two provided simulated narratives of a 'typical' case and one a detailed set of procedures with comments on principles. The narratives were analysed for order of information, topics included, key phrases related to the explanation of epilepsy and the emotional impact of the diagnosis. From these three accounts a list of topics and questions were derived. The epilepsy literature, commonly used for parents and children, was also reviewed for specific content and informed the questionnaire. These topics were then sent to a fourth consultant who made further suggestions. A questionnaire was then produced and modified by the four consultants (see [Appendix A](#) for finalised questionnaire).

The questionnaire is in three parts. (i) The content of the consultation(s): the main topics, rated as those that should be addressed in the first consultation or later. (ii) How consultants give the diagnosis: the words used and the points of emphasis. (iii) Asking what written and video materials they used.

## THE SURVEY

The questionnaire was sent to 32 consultant paediatric neurologists (about 75% of those in practice in the UK at this time); 20 replies (62.5%) were received over

a period of 8 months. Four replies were letters, the main theme of which was that it was not worthwhile to complete the questionnaire given the complexity and diversity of the task. Whilst one felt it was a 'pointless exercise', the other three wrote quite detailed accounts of their views and practice. These are not included in the analysis of the first section but are included in the later sections.

Thus 16 (50%) questionnaires were completed. One was relatively superficial with no additional detail, three were brief and 12 very detailed. Several made general comments mainly about the first part (Content). They ranged from '*this has proved to very difficult*' ( $n = 3$ ) and '*it is trying to be too prescriptive*' ( $n = 1$ ), to '*I found this useful as it made me re-think my own approach and our procedures*' ( $n = 1$ ). Two respondents stated it would be more useful to do this for specific types of epilepsy. Three noted they tend to see children later as a 'second opinion', after the initial disclosure one adding, '*often badly by others*'. Finally, one referred to the deluge of surveys currently experienced by many consultants, often producing nothing and categorised it under the '*yawn factor*'.

In this context, and given the specialist population contacted, meaningful responses from over half may be considered potentially worthwhile.

## RESULTS

The three questionnaire sections will be reported and discussed separately.

### Favoured consultation content

Table 1 summarises the number of respondents who felt the topic should be raised in the first (C1), second (C2) or a later consultation (CL), or only in special circumstances (SPC). One respondent only discussed the topics at the second consultation and later. Many wrote qualifications and clearly felt constrained by the rating procedure, though patterns did emerge and it is reasonable to conclude that respondents had some shared notion of commonality. For example in Section F.—General Management Issues, 13 respondents used the full range of rating from C1 to CL/SPC and 10 made a total of 22 qualifying comments. This indicates that they were making discriminative judgements. There was also evidence of within-respondent consistency in responding. For example, the pattern of responding is the same to question G—Voluntary groups and question H—Support Groups. Similarly at C1, 14 would discuss question D. Treatment Plans—how to get help—and 12, ques-

tion H. Sources of Help—Clinic. The distributions for Contacting Social Services or Social Worker are also similar.

Table 2 presents the data as percentages in decreasing order of frequency. If one includes topics probably in C1 but certainly discussed by C2, over 75% would also include type of seizures, remission, effects on brain and learning, medication, investigation plan, management of seizures, photosensitivity, sleep, lifestyle, contacting the school, and providing leaflets. One might view these topics as a typical medical agenda.

In contrast, sociopsychological topics associated with possible parental and child emotional reactions and adaptation had the highest rate of 'no' responses and were included by less than 20% at C1 and 50% at C2. The associated topics of Stigma and Telling Relatives and Friends, were also given low priority and would be included by less than 12.5% at C1 and 37.5 and 18.75%, respectively, at C2. Eight indicated that they would react to parental signs; two felt they had to be pro-active and raise the possibilities at the first interview, and so place it on the agenda for immediate or later discussion.

Some respondents stated or implied that most topics should be raised at the first interview, with the qualification '*depending on how the parents responded*' or '*how well they appeared to be coping with the information*'. Having raised the topic, the depth of discussion was left to parental reactions, later consultations, discussion by the specialist nurse, or as issues arose depending on later investigations. In contrast, others appeared to have a structured 'drip-feed' approach and reserved some topics for later consultations. Finally several only addressed topics if they were raised by parents or '*appeared to be an issue*'. A majority of respondents referred to the problem of having enough time to raise topics and address parents' questions. Those with a Liaison Nurse stated how important and useful this resource was, those without often stated their regret and were actively trying to recruit.

### Format—giving the diagnosis

The distinction between Questions 2.1 and 2.2(a) was not clear and so responses have been merged.

#### Q2.1. What is the best way to tell parents and children the diagnosis of epilepsy?

##### Q2.2.(a) What is epilepsy?

The restrictions of using a questionnaire format were noted, e.g. '*I don't give it in seven lines*'. Also the problem of some general format—'*depends upon*

Table 1: Frequency of responses to Section 1—Content.

Question	Responses					
	Cl	Cl-C2	C2	CL	SPC	No response
<b>A. Giving the diagnosis</b>						
Epilepsy	15		1			
Type of epilepsy		14	1	1		
Cause	15		1			
<b>B. Prognosis and explanation</b>						
Incidence	8	2	1	3	2	
Seizures						
Type	10	4	1	1		
Control of	13	1	1	1		
Remission	10	2	1	3		
Effects on brain, learning, behaviour	8	5	0	3		
<b>C. Stigma</b>						
	2	2	2	4	4	2
<b>D. Treatment plan</b>						
First aid	14			-2-		
How to get help	14			-1-		1
Medication						
Choice of drugs	14		1	1		
Side-effects	14		1	1		
<b>E. Investigation plan</b>						
More tests, observations to response to medication	9	4		3		
<b>F. General issues/management</b>						
Management of medication/how to avoid seizures	9	3			-4-	
Swimming, cycling, sports	13	1	1		1	
Photosensitivity, computers	10	2		1	2	1
Diet/alcohol	4	3	1	3	5	
Sleep/lifestyle	7	4	1	3	1	
Immunisation	6	3	2	1	4	
Hereditary/pregnancy	2	2	2	5	4	1
Other illness/drugs	3	2	2	3	4	1
<b>G. Contacting and telling others</b>						
The school	9	3	1	2	1	
Holidays/school trips	2	3	3	5	4	
Social services	2		2	4	6	
Voluntary groups	6		3	4	3	
Youth clubs/Brownies	1		2	5	8	
Relatives/friends	1		2	6	7	
<b>H. Sources of information/help</b>						
Leaflets	9	3	1	1	1	1
Books	6	2		-2-	3	2
Videos	3	2		-2-	5	3
Social worker	2	1		-2-	3	3
Support groups	6		3	-2-	2	2
Clinic—follow-up plan/contacts for help	12	1	1		2	
<b>I. Reactions and feelings</b>						
Initial parental reactions	3	2	2	2	2	5
Adjustment process	2	2	2	2	2	6
Child's reactions	3	2	1	4	2	4

*how much they know already', 'it is completely different for those that arrive after the first couple of seizures . . . from those with a large number of attacks where the family almost certainly knows something about epilepsy already'.*

#### Context

Several respondents noted contextual and procedural factors, i.e. include both parents or any other significant adults, siblings who are with them; if both parents

Table 2: Priority of topics at CI, C1 + C2, and later or in special circumstances.

	CI (%)	CI + C2 (%)	Later	SPC (%)	No response (%)
Epilepsy	93.75	100.00	0	0	0
Cause	93.75	100.00	0	0	0
Type of epilepsy	87.50	100.00	0	0	0
How to get help	87.75	93.75	0	0	6.25
Choice of drugs	87.50	93.75	6.25	0	0
Side-effects	87.50	93.75	6.25	0	0
First aid	87.50	87.50	12.50	0	0
Seizures—control of	81.25	93.75	6.25	0	0
Swimming, cycling, sports	81.25	93.75	0	6.25	0
Clinic—follow-up plan/contacts for help	75.00	81.25	6.25	0	12.50
Seizure type	62.50	93.75	6.25	0	0
Seizure remission	62.50	81.25	18.75	0	0
Photosensitivity, TV, computer, disco	62.50	75.00	6.25	12.50	6.25
Investigation plan	56.25	81.25	18.25	0	0
Contacting the school	56.25	81.25	12.50	6.25	0
Providing leaflets	56.25	81.25	6.25	6.25	6.25
Management of medication/avoid seizures	56.25	75.00	25.00	0	0
Effects on brain, learning, behaviour	50.00	81.25	18.75	0	0
Incidence	50.00	68.75	18.75	12.50	0
Sleep/lifestyle	43.75	75.00	18.75	6.25	0
Immunisation	37.50	68.75	6.25	25.00	0
Voluntary groups	37.50	56.25	25.00	18.25	0
Support groups	37.50	56.25	25.00	6.25	12.50
Books	37.50	50.00	31.25	6.25	12.50
Diet/alcohol	25.00	50.00	18.75	31.25	0
Other illness/drugs	18.75	43.75	18.75	25.00	6.25
Initial parental responses	18.75	43.75	12.50	12.50	31.25
Child's reactions	18.75	37.50	25.00	12.50	25.00
Videos	18.75	31.25	43.75	6.25	18.75
Holidays/school trips	12.50	50.00	31.25	25.00	0
Stigma	12.50	37.50	25.00	25.00	12.50
Adjustment process	12.50	37.50	12.50	12.50	37.50
Hereditary/pregnancy	12.50	37.50	31.25	25.00	6.25
Social services	12.50	25.00	25.00	37.50	0
Social worker	12.50	19.75	31.25	31.25	18.75
Youth clubs/Brownies	6.25	18.75	31.25	50.00	0
Telling relatives/friends	6.25	18.75	37.50	43.75	0

are not present at the consultation offer a further one as soon as possible; with the child present; with the permission of the parent(s), include a social worker or specialist nurse who can follow up the consultation, and have at least half an hour in a quiet room. One noted the difficulty of identifying who the parents should contact in an emergency, i.e. the specialist nurse, the GP, the general paediatrician, the paediatric neurologist. *'I think unlike other neurologists we probably make ourselves very available. This may be a noose around our neck but it is difficult for the families of children with epilepsy to know what to do for the best'*. Three emphasised the importance of not just talking to the parents but to try talking directly with the child depending on age.

#### Tone

Some respondents noted the, general 'tone' they aim for: be truthful/honest; realistic—not overly optimistic or pessimistic; try not to appear hurried; one

believed/hoped that this improved the relationship with the family and fostered trust and compliance.

#### Recurrent information themes

Seven recurrent factual points emerged from the brief written accounts.

- (a) It was important to say it is epilepsy.
- (b) Need to explain that seizures and fits and some convulsions are all the same.
- (c) That recurrent seizures are called epilepsy—*'and that this is all the term means'*.
- (d) Seizures can happen to anyone in certain circumstances.
- (e) Having a seizure is very common—*'try to counteract the connotations of the term epilepsy', 'the brain is still working all right and is not usually damaged by the seizure'*.

- (f) It may not be persistent (depending upon type).
- (g) Types of epilepsy and the implications/prognosis.

#### *Content order*

The timing of when the term epilepsy was introduced varied. The majority of respondents appeared to introduce it quite soon and then explain more about it. Others appeared to delay using the term until after they had talked about the seizures and explained something about how they occurred.

If there is a second visit to receive results, etc. . . . .  
I summarise the key points from the first visit, discuss the test results and then give the diagnosis of epilepsy . . . .

Having introduced the term epilepsy, some respondents then appeared to go straight into different types and prognosis whilst others appeared to ‘counteract the connotations of the term epilepsy’ emphasising how common it can be, famous people who have had it, the child is the same healthy child as before the episodes, the fits do not usually change the brain. The latter included all respondents who had made some comments about the need to recognise or address the emotional reaction that can occur to the diagnosis.

The following quotes illustrate the range of responses:

The attacks your child has had are called ‘seizures’ that is events caused by abnormal brain electricity making the body feel or act strangely. A tendency to have seizures is called epilepsy and that is what your child has.

The episodes your child is having are caused by sudden disturbances of the brain’s electrical activity. The episodes are epileptic seizures and people who tend to have these types of episodes are said to have epilepsy.

I think these attacks are seizures, also known as fits. These come under the general heading of ‘epilepsy’ which distinguishes them from faints or febrile convulsions. The use of the term epilepsy does not imply that the fits are permanent—that is they could go away in future [I try to emphasise that seizures do not usually change the brain].

You (he/she) are having recurrent convulsions [synonyms] . . . . This is because of abnormal electrical brain discharges. We call recurrent convulsions epilepsy. The conditions are common. We’ve found no serious brain disorders and with time and treatment, there’s an excellent chance of stopping your

convulsions happening. You (he/she) are the same healthy child that you were before the convulsions were recognised and it’s not going to be necessary to alter your life.

You have explained very clearly to me the attacks that J. . . has had. We think that these attacks are seizures or fits—these words all mean the same thing. Because you have had more than one, by definition, we call it epilepsy [very important at this point to explain that the word epilepsy just means having recurrent fits]—it doesn’t mean anything else about you. Apart from this tendency your brain works the same as anyone else’s. You are just as healthy. Saying you have epilepsy doesn’t tell us that the fits are going to continue. Anyone can have a seizure given sufficient stimulus. It is also very common [discuss prevalence] . . . then . . . can I explain more about what is happening in the brain to cause a seizure? I attempt to explain what is happening in the brain to cause a seizure—including why children and adults may be vulnerable at different ages. (1) Mention ‘imbalance’ between chemicals in the brain that ‘excite’ the brain and ‘calm’ the brain or switch nerve cells off again—these chemical signals are at work all the time. (2) If we had an EEG running during a seizure, the electrical sign is a ‘discharge’ or ‘burst of activity’.

It does look as though you have a tendency to have fits. This is caused by enough cells firing off simultaneously. This is what we see in the EEG. This is something the normal brain can do. If I starved you for 3 days, sat you next to a flickering TV set and made you drink a pint of whiskey you would possibly have a fit. Anybody who has a faint can have a fit [talk about *deja vu* and *sleep myoclonus*]. The normal brain works with a cocktail of chemicals, some of which encourage the nerve cells to fire and others which dampen them down. Whether it turns on or not depends on the exact balance of chemicals at any one time. Your cells have a tendency to fire off more spontaneously than others and then the mechanisms that stop the discharge from spreading falter momentarily and the discharge spreads. The fits do not themselves cause damage but can be a nuisance. The effect of anticonvulsants is to dampen down the tendency to fire off spontaneously but leave the brain’s normal electricity unimpaired.

Now the results from J. . . ’s EEG are to hand and they show an unusual pattern of electrical activity with his brain. To explain that a bit further . . . . We all have electrical activity going on in our brain. It’s

like a giant living computer made up of millions of nerve cells that are organised into networks. The EEG test looks at the patterns of electrical activity within that computer and helps us to localise any malfunction. [Use diagram of brain at this stage]. You are probably familiar with what the brain looks like. Essentially it has two parts . . . [briefly explain hemispheres localised function and spinal cord]. A malfunction in any part of this computer will give a different experience according to which part it affects. Now J. . . 's EEG has shown that some nerve cells in this area [indicate] are firing off spontaneously. I am sure that explains the funny do's he has from time to time. That is to say he has a form of childhood epilepsy. I would not let the talk of epilepsy fill your heart with fear. [Then explain seizure, incidence, treatment] . . .

**Q2.2.(b) How do you explain it to the younger child? (e.g. 5–10 years).**

Four respondents noted this was difficult, particularly for the young child (5–8), and one that it was not possible in the first consultation with the family or in the hospital but mainly done in a home visit(s) by the specialist nurse. Several referred to it being easier for the 9–10-year-old, noting it depended on the apparent ability of the child. Three stated they use a simpler version of what they told to parents and teenagers. Three stated their strategy was to give the explanations to the parent but to try to include the child in the discussion, then try to find out what the child has understood—with 'open questions' and encourage the child to ask questions. Two tried to find the child's name for the seizure and what they think about it. They then work from that giving explanations about messages sent out from the brain, it being a nuisance and would the child like to try to stop it by taking some medication?

Five respondents emphasised that they tried to convey to the child that 'it is not your fault', 'you are just as healthy as others', 'not stupid or naughty'. Three also emphasised it was quite common.

Four felt that with older children reference to computers could often help.

**Q2.2.(c) Are there any aids you find useful when explaining?**

There appeared to be some confusion with this question. Some respondents referred to leaflets and videos but did not indicate that they were used directly in the disclosure of epilepsy.

Of those directly related to the disclosure and explanation:

- Two commented 'not really' and two did not respond.

- Three sometimes used the EEG output and another various EEG traces taken from Epileptic Syndromes (Roger *et al.*) and two made reference to brain scan images.
- Three referred to drawing pictures. One drew simple pictures of the brain and described how a seizure began in a group of nerve cells and then spread out and excited surrounding ones until enough of an area is firing to produce a seizure.
- Four used a brain map to try to explain the origin and development of an attack one referencing Patient Guide to the Human Brain published by Ciba-Geigy and one referred to 3-D models of the brain. One stated, '*pictures of the brain may help*' but another that '*pictures of the brain don't help*'.
  - One stated, "if the child is computer literate—then occasionally I will draw an analogy to computers. There is a computer and keyboard on the clinic desk".
  - Two noted '*pictures, leaflets, e.g. NSE/BEA/ books etc.*' and another '*BEA leaflets*' and a third '*booklet appropriate to the syndrome and age of child*'.
  - Two referred to the Adventure Club Video (BEA). One referred to a video for adolescents and living with the difficult epilepsies.

**Q3. Are there words/phrases or analogies that you have found (a) helpful and (b) unhelpful?**

Four respondents gave no comments to this question.

- Unhelpful words/phrases: "*To use the term 'epilepsy' without qualification of the meaning for individual child/family*"; '*don't refer to people as epileptic only seizures*' . . . using '*epileptic as a noun*'.
- Helpful words/phrases: '*Treatment is to try to control electrical seizure discharges in the brain—it is not meant to calm you down or control you*'. One respondent felt it was helpful "*to describe famous people who had epilepsy—although this is usually more interesting to parents than the child*".
- Unhelpful analogies: Five respondents felt that lightning, thunderstorms, electrical storms and electrical discharges were unhelpful and that they could be very alarming. One noted throwing a stone into a pond and making waves (referring to a children's book), and one to telephone junction boxes—'*as most people have no idea of what they look like*'.

- Helpful analogies: In contrast one felt the analogy of telephone junction boxes was helpful and three included electrical discharges. Three referred to electrical circuits and short circuits in wiring. One referred to ‘*low seizure threshold*’ and ‘*reduced insulation which allows excessive electrical activity and which can be improved with antiepileptic medication*’. One referred to ‘*interference on TV... often intermittent and correctable. Can’t tell by looking at outside of the TV*’.

The most common analogy ( $n = 5$ ) was computers: ‘*If the child understands computers—refer to computer malfunction*’. ‘*Like a computer that develops an electrical short circuit—it makes it impossible for the brain to take in and deal with information*’; ‘*It’s like computer software—doesn’t help to take an X-ray of the computer if the software is faulty*’.

**Q4. At the first consultation do you give, lend or recommend any leaflets, books or videos to parents—if so, which?**

**Q5. Are there pamphlets, books, videos that you recommend at later consultations?**

There was little differentiation between the two questions and so the responses are considered together. Six respondents stated they did not use any additional materials. Five of these made comments. ‘*Perhaps I should*’; ‘*later the specialist nurse does this*’; ‘*a selection of material is available in the clinic for parents to look through and write off for*’; ‘*not unless asked—we have BEA leaflets in clinic*’; ‘*sometimes a few leaflets are available but charities charge now for bulk order... but free for parents... this is a disincentive to have them available*’.

Nine always tried to give or direct parents to material. Six stated they use various BEA leaflets. The most often cited was ‘Epilepsy and the Child’. One gave photocopies from the relevant section of ‘Epileptic Syndromes’; one had single sheets of information on the specific type of epilepsy related to individuals and one had a set of own-produced leaflets on specific epilepsy syndromes and the anticonvulsant prescribed which listed side effects. This consultant also used BEA leaflets, and books—‘Epilepsy: A Parents Guide’; ‘Hand in Hand’; ‘Junior Encyclopaedia of Epilepsy’ which were usually lent or less commonly, given to parents.

The following books were recommended:

Four respondents recommended, *Epilepsy: A Parent’s Guide* (MacMenamin and O’Connor). Two each recommended, *The Epilepsy Reference Book* (Jeavons and Aspinall), *The Illustrated Junior Encyclopaedia* (Appleton), *Hand in Hand Booklet*. One

each recommended, *Seizures and Epilepsy in Childhood: A Guide to Parents* (Freeman, Vining and Pillas), *Living with Epilepsy* (Chadwick and Usiskin) and *Epileptic Syndromes* (Rogers).

There were several comments about available videos: ‘*Most videos are too general*’; ‘*I occasionally use them—but not much*’; ‘*We offer videos but many parents refuse them*’. ‘*No appropriate videos for very young children less than 5 years old—no good ones until the teenage years, the Adventure Club video for 5–10-year-olds is worthwhile*’.

The specific videos mentioned were *Adventure Club* ( $n = 2$ ); *NSE video of different seizure types* ( $n = 1$ ); *Living with the Difficult Epilepsies* ( $n = 1$ ); *The Teenage Years* ( $n = 1$ ) and *Guide to Epilepsy-adolescents* ( $n = 1$ ).

On reviewing the content of these materials we formed the impression that there was no clear consensus in approach, content and use of analogy. It was also difficult to discern age differentials and there was little very little information or reading material produced for young children (5–7 years).

## DISCUSSION

There were clearly problems with the questionnaire approach to this topic: several respondents stated how they felt constrained; others refused to complete some sections and there were indications of misunderstanding of questions. Even so many wrote at great length and there was evidence of discriminative responding. Given the specialist nature of the participants and topic, it is felt the results are worthwhile and point to issues and future investigation. Nevertheless, our aim to arrive at a consensus of opinion from which a model for evaluation could be derived was clearly over optimistic. Whilst this may reflect the method of information gathering, it also appears to reflect the current status of disclosure practice and the heterogeneity of the epilepsies.

The most striking impression from the replies is a general lack of consensus, and that the thoughts of, and approaches to disclosing the diagnosis by the paediatric neurology consultants involved are largely determined by intuition rather than a shared knowledge of the processes involved. Several felt the topic was too complex, with too many variables to allow an agreed and more formalised procedure to be developed. Some felt it would be undesirable. The notion appeared to be that individual improvisation and intuition based on experience was the only practical approach. In contrast, others had quite clear procedures and distinct ideas of what should and should not be done including the development and use of other staff and materials.

In terms of content, there was consensus about the medical information given during the disclosure consultation but not psychosocial and emotional topics. The respondents were split between those who felt it was important to address such issues, with no consensus on when, and those who appeared to ignore them. However, those respondents who felt sociopsychological matters should be included were more likely to do so at the second consultation. This is surprising since most parents experience emotional reactions and need to talk to others at the time, or shortly after, learning about the diagnosis. Given the number of respondents who would not include the topic of parental reactions, and how to address these reactions, in an early consultation, it was surprising that none commented that too often pathology is assumed when many parents cope well. No respondent suggested that parental reactions depend on the type of epilepsy, and hence its implications.

The most common themes in consultation content were that everyone's brain has the potential to have a seizure and a recurrent tendency to a disturbance of electrical activity in the brain along with the clinical consequences is referred to as epilepsy. There was then increasing disparity about to what extent nomenclature was explained, how seizure type might reflect the origins of seizure discharge and how the feelings of the recipient of the news might be acknowledged. Respondents were agreed that the younger the child the more difficult it is to explain epilepsy to them. The most frequent theme in this section was to emphasise that the child is healthy and not stupid, and it is not their fault.

There was consensus about some context variables such as access to a Liaison or Specialist Nurse or Social Worker and time—the feeling being that such resources would help with the problem of providing the range and depth of information required. This is in keeping with the opinion of those in adult practice (Dilorio and Manteuffel<sup>16</sup>). In this study, 73 nurses and 38 adult neurologists and neurosurgeons agreed that nurses are the preferred providers of information related to psychological concerns of those with epilepsy whereas physicians are the preferred providers of information about its cause and treatment. Our study identified a preference for the same complementary approach with doctors liaising closely with nurses, but there appeared to be little agreement and limited knowledge about the range and quality of supportive reading and audio–visual material. Some respondents appeared to be committed to the idea and had extensive materials, including 'in-house' leaflets, whilst others did not use any supportive material.

There was disagreement about how to explain what epilepsy is and the use of analogies and visual aids.

Overall the respondents were unsure about the value of analogy. Lightning, thunderstorms, etc. were felt to be unhelpful and alarming whilst the notion of electricity, wiring, short circuits and electrical discharge was common. There was disagreement about using the analogy of a telephone exchange, and how the notion of computers might be used. Two themes are apparent. One concerns wires, circuits and electricity and the other information exchange. Interestingly, none refer to chemical imbalance in this section on analogy, yet the verbatim descriptions noted earlier include explanations concerned with chemical imbalance, transmission along nerves, gated release of charged ions—i.e. current medical knowledge of the cause of epilepsy.

The comment that few people would have any idea of what a telephone exchange looks like, raises a further issue. The function of an analogy is to help explain an idea by using a similar idea that should be more familiar to the recipient. One might ask then how many of the parents and children would be any more familiar with the working of a computer, or electrical wiring circuits than they are with telephone exchanges. The question raised is whether explanations of how cells and nerves function are any less familiar or more complicated than explaining circuitry. Thus, given that there is no obvious or accepted analogy, it may be preferable to avoid them. The use of the computer analogy may be questioned from a broader perspective. Much of the explanation is reductionist and bio-mechanistic. The brain is not like a computer—the computer has been invented to perform some aspects of the human brain. Therefore, we feel that we need to develop a simple biological explanation.

In terms of the format, two models appeared. The first concerns when to introduce the term, epilepsy, in the disclosure and the second on how subsequently to provide information. Some respondents appeared to introduce the term quite early and then follow with detailed explanations. Presumably this avoids the danger of being criticised for procrastination and the risk of conveying stigma by avoiding the label. Others prefer to state the evidence upon which the diagnosis is based with some explanations, e.g. how seizures occur, before stating the word epilepsy. Presumably this 'lead-in' approach provides credible evidence to support the diagnosis which may reduce the risk of denial. It may also forewarn the parent that something is wrong and reduce the shock reaction and associated risk of being less able to assimilate later information.

The second model to emerge related to the content of the consultation. Three approaches are characterised by the qualitative and descriptive data recorded: 'pro-active', 'reactive' and 'drip-feed'.

The pro-active approach consists of laying out a comprehensive range of topics that might need to be addressed. Given a wide range of topics, the pro-active approach runs the risk of information overload with little being remembered, and creating a feeling of being overwhelmed and an inability to cope. The two respondents, who most clearly described this approach, also noted how they used prepared written information on standard topics and a Liaison Nurse as part of their strategy. Underlying this approach is the belief that parents have the right to all information and only they can identify what is important to them. In a sense it recognises that they will have an agenda that may be different to the consultant's agenda. It also recognises that most parents are bewildered and unprepared when they first encounter such information. Consequently, they often do not know what questions to ask and whether they should raise certain issues with the consultant. Hence, providing a 'cafeteria' of topics provides an initial framework from which they can choose or begin to choose their individual programme. It may reduce the numbers who later state they were not told essential facts or who felt that certain topics were not up for discussion with the doctor.

The reactive approach reduces the possibility of overload and tries to be more individually tailored to immediate needs. It does not initiate certain topics unless indicated by the parent. This assumes that the doctor can judge parental reactions and that parents have the necessary skills to raise questions. Many parents in these situations describe how surprised they were at remaining calm, with their emotional reactions emerging later in the safety of their home; others note that they were stunned and could not think of the questions to ask or did not know what to ask because of a lack of knowledge; others just want to distance themselves from the 'painful' context as soon as possible. Even those who may be expecting unwanted news may not have the necessary assertive skills or knowledge to raise questions. The reactive approach may be more comfortable for doctors as complex and emotional issues are less likely to be raised and the less time will be required in the consultation.

The drip-feed approach appears to be more protective of the parent and tries to prevent immediate over-load. Whilst it can address all/most topics, it pre-selects a specific order in relation to the situation. The assumption is that the consultant has a fairly clear idea of the topics and priorities and the likely agenda and needs of the parent. The results partly support this as most respondents had a clear idea of the information they would give and indicated some preferred order to several consultations. They also did not suggest additional topics to those listed, but two emphasised

the issue 'do fits cause brain damage?' However, there was disagreement about the priority of some topics and there is little available information of the match between the consultants agenda and preferred order and that of parents.

## CONCLUSIONS

From our findings it does seem reasonable to argue that patient dissatisfaction is not just associated with factors related to family and condition variables, or to the context variables. A major source of variance arises from the way the consultant gives the disclosure, which concerns their perspective and models about what is important. Thus patient dissatisfaction may not be inevitable because 'bad' news is being given and might be reduced if more appropriate frameworks and procedures were developed and evaluated.

Our aim in carrying out this survey was to find consensus from which to establish agreed guidelines. Clearly the results indicate that this is still some way off. However, the results do offer a number of directions for further work.

The first is to develop more detailed models of the disclosure process, e.g. 'reactive', 'pro-active' and 'drip-feed', which can be operationalised and evaluated. The second is to arrive at explanations of epilepsy which can then be tested with consumers from young children to parents. The third is developing a topic list from the consumers and use this to inform the order and content of the disclosure consultation and subsequent information delivery and support. The fourth is to develop evaluated supportive material which is integrated into the disclosure process and informed by patient needs and their adaptation to potentially bad news.

Arguably, one of the most important things neurologists do with people they meet in consultations is to talk to them and offer advice and information. Furthermore, as one respondent noted, there will increasingly be a requirement in Common Law to meet standards of information delivery. The time has come to analyse more closely the content of such consultations specific to conditions. Hopefully, the information that has emerged from this survey provides some guidance about how and when to disclose epilepsy and also identifies future areas of study.

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## Appendix A THE DISCLOSURE INTERVIEW(S)

## A.1. Content

- What should be discussed at the first appointment after the epilepsy has been diagnosed? (Please denote C1 for Consultation I.)
- What is best left to the second appointment (C2)
- What is best left to later appointments (CL) or discussed only in special circumstances (SPC).

	Response (e.g. C1, C2, C3, SPC)	Comment (any observations welcome)
A. <i>Giving the diagnosis</i>		
Epilepsy		
Type of epilepsy		
Cause		
B. <i>Prognosis and explaining epilepsy</i>		
Incidence		
Seizures		
Type		
Control of		
Remission		
Effects on brain, learning behaviour, to the parent(s), to the child (4–14 years)		
C. <i>Stigma</i>		
Views and fears of others, etc.		
D. <i>Treatment plan</i>		
First aid (e.g. recovery position)		
How to get help		
Medication		
Choice of drugs		
Side-effects		
E. <i>Investigation plan</i>		
More tests? Parental observations, response to medication, timetable		
F. <i>General issues/management</i>		
Parent management of medication, child's understanding, how to avoid seizures		
Swimming, cycling, contact sports, etc.		
Photosensitivity, disco's, TV, computers, diet, alcohol		
Sleep (quantity), lifestyle, Immunisation		
Hereditary, pregnancy		
Other illness, drugs		
G. <i>Contacting and telling others</i>		
The school		
Holidays/school trips		
Social services		
Voluntary organisations		
Youth clubs/Cubs/Brownies		
Relatives and friends		
H. <i>Sources of information/help</i>		
Leaflets		
Books		
Videos		
Support groups		
Social worker		
Clinic—describe follow-up		
Plan/contact for help		
I. <i>Reactions to the diagnosis</i>		
Parental reactions, e.g. shock or relief, anger, confusion, anxiety		
Adjustment process, e.g. understanding feelings, appraisal of implications, gaining control through information and experience, use of social support and coping strategies/resources		
Child's reactions, e.g. fear, worries, confusion, effect on friends		
J. Additional topics or comments		

## A.2. Format—giving the diagnosis

1. What is the best way to tell parents and children the diagnosis of epilepsy?  
Given that you have sufficient evidence to make a diagnosis, would you write down verbatim how you prefer to go through it (please continue overleaf, if necessary):
2. What is epilepsy?
  - (a) How do you explain to the parent and teenager what epilepsy is?
  - (b) How do you explain it to the younger child (e.g. 5–10 years)?
  - (c) Are there any aids you find useful when explaining—if so please give details?
3. Are there words/phrases or analogies that you have found?
  - (a) Helpful
  - (b) Unhelpful
4. At this first consultation do you give, lend or recommend any leaflets, books or videos to parents—if so which?
  - (a) give:
  - (b) lend:
  - (c) recommend:
5. Are there pamphlets, books, videos that you only recommend (give or lend) at later consultations or in special, circumstances? If so please give details:

Many thanks for your help. We will be in touch again as soon as we have collected the responses.

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