

Supplemental File 4: Parent Perspectives on Communicating about Epilepsy

I usually talk to my child about his/her epilepsy when...	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my child about his/her epilepsy
My child has a seizure	71	70.4%	21.1%	8.5%	0%
My child takes his/her medication	70	38.6%	40%	21.4%	0%
My child asks me questions	72	76.4%	19.4%	4.2%	0%
My child has a hospital appointment coming up/has recently had one	71	76.1%	19.7%	4.2%	0%
My child's medication is causing difficulties	72	58.3%	16.7%	25%	0%
My child cannot partake in an activity due to his/her epilepsy	72	44.4%	22.2%	30.6%	2.8%
My child is worried/upset	72	62.5%	27.8%	9.7%	0%
My child needs support	72	70.8%	22.2%	6.9%	0%
When I talk to my child about his/her epilepsy, we talk about...	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my child about his/her epilepsy
What epilepsy is	72	68.1%	29.2%	2.8%	0%
How my child feels about having epilepsy	71	62%	35.2%	2.8%	0%
What happens when my child has a seizure (e.g. – how he/she appears)	71	67.6%	25.4%	7%	0%
My child's medication	72	80.6%	16.7%	2.8%	0%
Medication side effects	72	48.6%	33.3%	18.1%	0%
My child's hospital appointments	72	76.4%	18.1%	5.6%	0%
Restrictions my child experiences due to his/her epilepsy	72	45.8%	30.6%	22.2%	1.4%
My child's seizure control (or lack thereof)	72	58.3%	25%	15.3%	1.4%
Whether my child will grow out of his/her epilepsy	72	48.6%	34.7%	15.3%	1.4%
I talk to my child about his/her epilepsy because...	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I never talk to my child about his/her epilepsy
I don't want my child to feel different	72	84.7%	6.9%	8.3%	0%
I want my child to know what he/she should do in the event of a seizure	72	75%	22.2%	2.8%	0%
It helps my child to deal with certain situations	72	79.2%	16.7%	4.2%	0%
It helps me to deal with certain situations	72	65.3%	23.6%	11.1%	0%
I want my child to be informed about his/her epilepsy	72	88.9%	11.1%	0%	0%
I don't want my child to keep secrets about his/her epilepsy	72	77.8%	19.4%	2.8%	0%
I don't talk to my child about his/her epilepsy because...	N	Really true for me	Sort of true for me	Not at all true for me	Does not apply, I always talk to my child about his/her epilepsy
I don't want to single my child out in comparison to his/her siblings	69	15.7%	12.9%	34.3%	37.1%
I don't want to worry my child	70	24.3%	14.3%	25.7%	35.7%
I don't want my child to dwell on his/her epilepsy	69	31.9%	13%	23.2%	31.9%

Do any of the following encourage or discourage you to talk to your child about his/her epilepsy?	N	This encourages me	This discourages me	Does not apply, this has no impact on how much I talk to my child about his/her epilepsy
My child's disposition (i.e. – your child's temperament and nature)	71	54.9%	19.7%	25.4%
The amount of time my child has had epilepsy	70	51.4%	7.1%	41.4%
The level of information I have about my child's epilepsy	71	60.6%	11.3%	28.2%
My child's seizures are well controlled	71	67.6%	7%	25.4%
Portrayals of epilepsy in the media	71	39.4%	16.9%	43.7%
Do any of the following encourage or discourage you to talk to your child about his/her epilepsy?	N	This encourages me	This discourages me	Does not apply, this has no impact on how much I talk to my child about his/her epilepsy
My own attitudes towards epilepsy	71	62%	4.2%	33.8%
Experiences I had with epilepsy prior to my child's diagnosis	71	29.6%	12.7%	57.7%
Talking about epilepsy with my child makes me feel...	N	Yes	No	Does not apply, I never talk to my child about his/her epilepsy
Reassured	71	85.9%	14.1%	0%
Optimistic	67	88.1%	11.9%	0%
Anxious	67	32.8%	67.2%	0%
Uncomfortable	68	10.3%	89.7%	0%
Pessimistic	67	9%	91%	0%