

Supplemental File 3: CWE Perspectives on Communicating about Epilepsy

I usually talk to my Mum or Dad about 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 Mum or Dad about epilepsy
I have a seizure	44	59.1%	31.8%	6.8%	2.3%
I take my medication	45	40%	40%	20%	0%
My medication is causing me difficulties	44	54.5%	22.7%	22.7%	0%
I have a question about epilepsy	45	51.1%	44.4%	4.4%	0%
I have a hospital appointment coming up/have recently had one	45	60%	35.6%	4.4%	0%
I cannot take part in an activity because of my epilepsy	45	33.3%	26.7%	40%	0%
I am worried/upset	45	40%	26.7%	33.3%	0%
I need support	45	35.6%	22.2%	42.2%	0%
When I talk to my Mum or Dad about 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 Mum or Dad about epilepsy
What epilepsy is	45	33.3%	42.2%	24.4%	0%
How I feel about having epilepsy	45	33.3%	44.4%	22.2%	0%
What happens when I have a seizure (e.g. – what I look like)	45	53.3%	33.3%	13.3%	0%
My medication	45	53.3%	42.2%	4.4%	0%
Medication side effects	45	44.4%	24.4%	31.1%	0%
My hospital appointments	45	51.1%	48.9%	0%	0%
Things I cannot take part in because of my epilepsy	45	33.3%	28.9%	37.8%	0%
Whether my seizures are controlled or not	45	40%	22.2%	37.8%	0%
Whether I will grow out of my epilepsy	45	48.9%	33.3%	17.8%	0%
I talk to my Mum or Dad about my 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 Mum or Dad about epilepsy
I don't want to feel different	45	22.2%	31.1%	46.7%	0%
I want to know what I should do if I have a seizure	45	33.3%	28.9%	37.8%	0%
It helps me to deal with certain situations	45	28.9%	40%	31.1%	0%
I want to know a lot about my epilepsy	45	35.6%	37.8%	26.7%	0%
I don't want to keep secrets about my epilepsy	45	44.4%	26.7%	28.9%	0%
I don't talk to my Mum or Dad about my 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 Mum or Dad about epilepsy
I don't want to feel different	44	13.6%	15.9%	56.8%	13.6%
I don't want to worry my Mum or Dad	45	20%	15.6%	51.1%	13.3%
I don't want my Mum or Dad to think I am looking for attention	44	11.4%	18.2%	56.8%	13.6%
If I talk to my Mum or Dad they might not let me go to things	45	15.6%	17.8%	53.3%	13.3%
My Mum or Dad will make a big deal about it	45	13.3%	13.3%	60%	13.3%
Do any of the following things make it helpful or challenging for		This helps	This makes it		

me to talk to my Mum or Dad about my epilepsy?	N	me	difficult	This makes no difference
How much I usually talk to my Mum or Dad about things	45	44.4%	6.7%	48.9%
The amount of time that I have had epilepsy	45	35.6%	11.1%	53.3%
How much I know about my epilepsy	45	48.9%	13.3%	37.8%
How often I have seizures	45	33.3%	24.4%	42.2%
When epilepsy is on the T.V. or radio	45	37.8%	6.7%	55.6%
How I feel about my epilepsy	45	37.8%	26.7%	35.6%
Talking about epilepsy with my Mum or Dad makes me feel...	N	Yes	No	Does not apply, I never talk to my Mum or Dad about my epilepsy
Happy	44	54.5%	45.5%	0%
Sad	44	27.3%	72.7%	0%
Worried	44	31.8%	68.2%	0%
Brave	44	52.3%	47.7%	0%
Embarrassed	44	15.9%	84.1%	0%
Different	44	29.5%	70.5%	0%
Special	43	18.6%	81.4%	0%