

## Outcomes after SUDEP disclosure

Author, year	Anxiety, fear or depression	Medication adherence	Changes in behaviour	Satisfaction with information											
Whitney, 2023 (descriptively reported)	“Anxiety/fear related to SUDEP disclosure was generally not long-lasting”		“Caregivers were more likely to make lifestyle/ management changes due to learning about SUDEP (e.g., increased supervision and co-sleeping)”	“When asked if, given another chance, participants would still have liked to receive the knowledge”											
Safarpour Lima, 2024	No difference before and after information <i>HADS</i> : MD (SD) -0.5 (± 3.82)	Increase after information <i>MMAS-8</i> : MD (SD) 1.36 (± 0.9)	Increase after information <i>Bathing safety</i> (score 0-3): MD (SD) 0.46 (± 0.7) <i>Sleep safety</i> (score 0-3): MD (SD) 0.47 (± 0.7) <i>Preparation for seizure</i> (score 0-2): MD (SD) 0.66 (± 0.6)												
Pan, 2023	<i>HAMA</i> score increased directly after disclosure (mean 12.84 ± 7.00; compared to baseline 6.64 ± 4.54), but normalization after 5 weeks (mean 6.96 ± 5.25)			>75% indicated that SUDEP information was more beneficial than detrimental											
Kumari, 2022	No significant change Depression, anxiety or stress ( <i>DASS-21</i> ) at one month compared to baseline <table><tr><td></td><td>Baseline</td><td>1 month</td></tr><tr><td>D</td><td>4.1 (± 4.7)</td><td>3.7 (± 4.6)</td></tr><tr><td>A</td><td>3.8 (± 3.7)</td><td>3.8 (± 3.8)</td></tr><tr><td>S</td><td>8.6 (± 5.9)</td><td>9.2 (± 5.7)</td></tr></table>		Baseline	1 month	D	4.1 (± 4.7)	3.7 (± 4.6)	A	3.8 (± 3.7)	3.8 (± 3.8)	S	8.6 (± 5.9)	9.2 (± 5.7)	84.2% of parents changed >2 epilepsy-related childcare behaviours (mostly administration of ASM at fixed time, regular exercise, supervision of activity, having seizure action plan, rescue medications, and inform school – with epilepsy information, emergency contact and seizure action plan)	
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Wadle, 2022	Depression ( <i>NDDI-E</i> ) Mean (SD) 11.7 ± 4.2 (compared to 12.2 ± 4.0 at baseline)  Moderate or high worry (seizure worry scale): -13.2% after 3 months compared to baseline		43.4% of patients reported no behavioural adjustments; 31.6% slight adjustments and 24% strong adjustments	More than 85% of participants were satisfied with receiving SUDEP information No change in quality of life ( <i>EQ-5D</i> ) after 3 months (score 0-1): MD (SD) 0.008 (± 0.378) No change in epilepsy stigma scale after 3 months: 38.7% no stigma (29.4% at baseline) and 6.4% high stigma (same as baseline)											

**Abbreviations:** *DASS-21*: Depression, Anxiety and Stress Scale-21 (score 0-21 per subscale, with scores ≥14; ≥10 and ≥17 respectively indicating extremely severe complaints) ,*HADS*: Hospital Anxiety and Depression Scale (score 0-42, higher is more anxiety), *HAMA*: Hamilton Anxiety rating scale (score <14 is asymptomatic), MD: Mean difference, *MMAS-8*: Morisky medication adherence scales (score 0-8, higher is better adherence),*NDD-IE*: Neurological Disorders Depression Inventory for Epilepsy (score 6-24, with a score ≥14 indicative of depressive mood) , SD: standard deviation