

# Epilepsy

## Transition to Adult Care

H. Terry Hutchison MD PhD  
Clinical Professor Neurology and Pediatrics  
UCSF Fresno 559-264-9100  
Cell: 559-260-2148



**Danielle M. Andrade**  
is an adult  
epileptologist and  
Chair of the Transition  
Guidelines Working  
Group.

## **Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force**

**<sup>1\*</sup>Danielle M. Andrade, <sup>2</sup>Anne S. Bassett, <sup>3</sup>Eduard Bercovici, <sup>4</sup>Felippe Borlot, <sup>3</sup>Esther Bui, <sup>5†</sup>Peter Camfield, <sup>6</sup>Guida Quaglia Clozza, <sup>7</sup>Eyal Cohen, <sup>8</sup>Timothy Gofine, <sup>9</sup>Lisa Graves, <sup>10</sup>Jon Greenaway, <sup>11†</sup>Beverly Guttman, <sup>12</sup>Maya Guttman-Slater, <sup>13</sup>Ayman Hassan, <sup>14</sup>Megan Henze, <sup>15</sup>Miriam Kaufman, <sup>16</sup>Bernard Lawless, <sup>17</sup>Hannah Lee, <sup>18</sup>Lezlee Lindzon, <sup>19</sup>Lysa Boissé Lomax, <sup>20</sup>Mary Pat McAndrews, <sup>21</sup>Dolly Menna-Dack, <sup>22,23</sup>Berge A. Minassian, <sup>14</sup>Janice Mulligan, <sup>24</sup>Rima Nabbout, <sup>25</sup>Tracy Nejm, <sup>26</sup>Mary Secco, <sup>27</sup>Laurene Sellers, <sup>28</sup>Michelle Shapiro, <sup>29</sup>Marie Slegr, <sup>30</sup>Rosie Smith, <sup>31†</sup>Peter Szatmari, <sup>32</sup>Leeping Tao, <sup>33</sup>Anastasia Vogt, <sup>34</sup>Sharon Whiting, and <sup>35</sup>O. Carter Snead III**

*Epilepsia*, 58(9):1502–1517, 2017  
doi: 10.1111/epi.13832

# Steps in Transition to Adult Care

- Step 1 **12-15 years** Introduce the Concept of Transition
- Step 2 **12-17 years** Explore Financial, Community and Legal Support
- Step 3 **16-17 years** Transition Readiness
- Step 4 **12-19 years** Risk Factors for Unsuccessful Transition

# Step 1 12-15 years Introduce the Concept of Transition

- Family Centered
- Parents make decisions
- Pediatric Hospital
- Dependent transportation
- Home/School
- Parents for Rescue
- Behavior support
- Parents give meds



- Patient Centered
- Patient participates in decisions
- Adult Hospital
- Driving / Public transportation
- Work/Program
- Risk of being alone
- Self Control
- Responsibility

# Step 2 12-17 years Explore Financial, Community and Legal Support

- ◉ CCS goes away
- ◉ Dependent on parents insurance
- ◉ Aging/Retiring parents
- ◉ Schools and Child Development Agencies
- ◉ Driving
- ◉ Conservatorship or Medical Power of Attorney

# Step 3 16-17 years Transition Readiness

## My child

- Can describe condition
- Takes part in care
- Organizes health information
- Can get to visits
- Speaks up to providers
- Plans for stress, depression, anxiety
- Understands prognosis
- Knows medical insurance
- Knows effect of drugs, alcohol, sleep
- Talks about sexual health, contraception
- Network of friends and community
- Career choices
- Knows driving rules
- Knows human rights

# Step 3 16-17 years Transition Readiness

As a parent, I

- Know my child's rights to confidentiality and privacy
- Am aware of community resources to assist me in transition
- Am working on transition plan
- Am ready for housing needs for my child
- Understand insurance, and estate planning
- Have confidence in teaching self-advocacy
- Talk with my child about career and life plan

# Step 4A 12-19 years Risk Factors

- Inconsistent adherence to medicine
- Erratic sleep patterns
- Alcohol and drugs
- Risk of pregnancy and other gender/sexual issues
- Driving and seizures
- Depression, anxiety, psychiatric disorders



# Step 4B 12-19 years Risk Factors

- Lack of Age/Disability appropriate facilities/personnel for provision for EEG, imaging, blood work
- Adult MD's unfamiliar with Childhood-onset Epilepsies
- Epileptic Syndromes
  - > Intellectual and Developmental Disabilities
  - > Lennox-Gastaut, Dravet, Angelman

# Many now known Genetic causes of Epilepsy

Invitae Genetics Panel – 125 genes

ADSL	ALDH5A1	ALDH7A1	ALG13	ARHGEF9	ARX	ATP1A2	ATP1A3
ATRX	BRAT1	C12orf57	CACNA2D2	CASK	CDKL5	CHD2	CHRNA2
CHRNA4	CHRN2	CLN2 (TPP1)	CLN3	CLN5	CLN6	CLN8	CNTNAP2
CSTB	CTSD	DEPDC5	DNAJC5	DNM1	DYRK1A	EEF1A2	EFHC1
EHMT1	EPM2A	FOLR1	FOXP1	FRRS1L	GABRA1	GABRB3	GABRG2
GAMT	GATM	GLRA1	GNAO1	GOSR2	GRIN1	GRIN2A	GRIN2B
HCN1	HNRNPU	IER3IP1	IQSEC2	ITPA	KANSL1	KCNA2	KCNB1
KCNC1	KCNH2	KCNJ10	KCNQ2	KCNQ3	KCNT1	KCTD7	KIAA2022
LGI1	LIAS	MBD5	MECP2	MEF2C	MFSD8	NGLY1	NHLRC1
NRXN1	PACS1	PCDH19	PIGA	PIGN	PIGO	PLCB1	PNKD
PNKP	PNPO	POLG	PPT1	PRICKLE1	PRRT2	PURA	QARS
ROGDI	SATB2	SCARB2	SCN1A	SCN1B	SCN2A	SCN3A	SCN8A
SCN9A	SERPINI1	SGCE	SLC13A5	SLC19A3	SLC25A22	SLC2A1	SLC35A2
SLC6A1	SLC6A8	SLC9A6	SMC1A	SNX27	SPATA5	SPTAN1	STX1B
STXBP1	SYN1	SYNGAP1	SYNJ1	SZT2	TBC1D24	TCF4	TSC1
TSC2	UBE3A	WVOX	ZDHHC9	ZEB2			

Preliminary Evidence – 58 genes

Glycine encephalopathy, FLNA, PTEN, RANBP2 – 5 genes

# Additional Step 5: Reevaluate the Epilepsy Diagnosis

- Psychogenic Non-Epileptic Seizures PNES
- Seizure semiology (types of seizures)
- EEG, ambulatory and video-monitoring
- Imaging
- Genetic testing

# Step 6: Barriers to Treatment-Resistant Epilepsy

- Adult providers unfamiliar with Childhood-Onset epileptic syndromes
- Neuromodulation – VNS and RNS
  - > Expertise and equipment
  - > Placement surgery and replacement
- Diet therapy – ketogenic diet
- Emergency Room expertise
- Hospital expertise
- Review Transition Readiness (Step 3)

# Step 7 Prepare a Pediatric Discharge Package

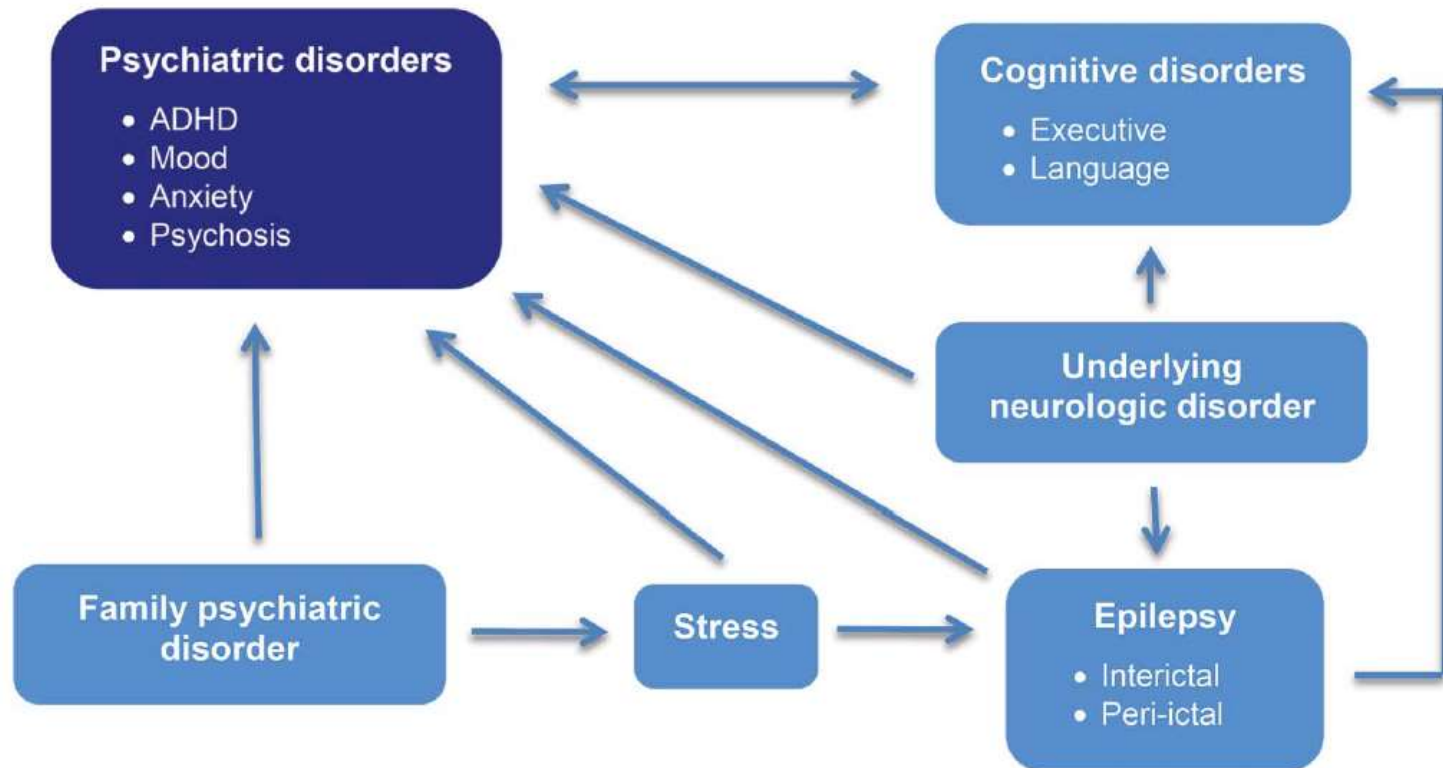
- Epileptic syndrome and causes
- Age of onset, seizure history
- Seizure types (including PNES) and behavioral effects of seizures
- EEG, Imaging and laboratory findings
- Precipitating factors
- Neurological examination
- Intellectual evaluation

# Step 7 Prepare a Pediatric Discharge Package

- Impairment      Disability      Handicap  
Function      Activity      Participation
- Medication history and failures, allergies
- Seizure rescue medicines, history of status epilepticus, seizure frequencies
- Dietary therapy, cannabis, alternatives
- Surgical history, seizure surgery, RNS or VNS
- Goals of care
- Psychiatric comorbidities

# Psychiatric Disorders and IDD

**Figure 2** Factors contributing to the genesis and persistence of psychiatric disorders in patients with intellectual and developmental disabilities and epilepsy



## Long-term effects of a multidisciplinary transition intervention from paediatric to adult care in patients with epilepsy

R.P.J. Geerlings<sup>a,\*</sup>, A.P. Aldenkamp<sup>a,b,c,d</sup>, L.M.C. Gottmer-Welschen<sup>a</sup>, A.L. van Staa<sup>e,f</sup>, A.J.A. de Louw<sup>a,b</sup> *Seizure*. 2016 May;38:46-53.

## Behavioral health in young adults with epilepsy: Implications for transition of care

Janelle L Wagner<sup>a,b,c,\*</sup>, Dulaney A. Wilson<sup>d</sup>, Tanja Kellermann<sup>e</sup>, Gigi Smith<sup>a,b,c</sup>, Angela M. Malek Braxton Wannamaker<sup>b,f</sup>, Anbesaw W. Selassie<sup>d</sup> **Epilepsy Behav.** 2016 Dec;65:7-12.

[Delivery of epilepsy care to adults with intellectual and developmental disabilities.](#)

17. Devinsky O, Asato M, Camfield P, Geller E, Kanner AM, Keller S, Kerr M, Kossoff EH, Lau H, Kothare S, Singh BK, Wirrell E. *Neurology*. 2015 Oct 27;85(17):1512-21.

## The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, and psychological issues

Peter Camfield<sup>a,b,\*</sup>, Carol Camfield<sup>a,b</sup>, Kanetee Busiah<sup>c</sup>, David Cohen<sup>d</sup>, Alison Pack<sup>e</sup>, Rima Nabbout *Epilepsy & Behavior* 69 (2017) 170-176