



# PROGRAM OF ACTIVE CONSUMER ENGAGEMENT IN EPILEPSY SELF-MANAGEMENT

## WHAT IS PACES?

### THE GOAL

The goals of PACES is to increase the medical, psychosocial, and community adjustment of adults with active seizure conditions.

### 8 SESSIONS COVER THE FOLLOWING TOPICS:

- ✓ Epilepsy and Medical Issues
- ✓ Dealing with Stress and the Blues (I)
- ✓ Dealing with Stress and the Blues (II)
- ✓ Compensating for Cognitive Challenges
- ✓ Epilepsy and Medical Issues
- ✓ Getting the Most out of Community Living
- ✓ Managing My Epilepsy Care
- ✓ Effective Communication about My Epilepsy
- ✓ My Health & Well-Being

PACES is an eight-session epilepsy self-management program developed with direct input from adults with epilepsy at the University of Washington Epilepsy Center/ Health Promotion Research Center and subject to randomized control evaluation with funding from the Centers for Disease Control (CDC).



### PACES DEVELOPMENT

PACES was developed through an extensive survey of 225 adults recruited across two Seattle epilepsy centers. The response rate was high (61%) with strong response reliability. Respondents identified their most important adjustment concerns and also the program elements that were important to them (viz., number and length of sessions, delivery modality, intervention approach, leadership, session schedule, etc.). Based upon the prevalent responses related to depression and attention/memory concerns, coping strategies in these areas are emphasized in specific modules and throughout the program.



### KEY PROGRAM ELEMENTS

- Qualified facilitator tandem to include a trained epilepsy mental health professional and a trained peer with epilepsy
- Mode of delivery involves an education component, assistance with coping strategy development, and goal setting.
- Delivery method is at participant's choice: on-site or by telephone. A web-based program is being investigated.



### PROGRAM EFFECTIVENESS

In the first randomized control trial (RCT), the program significantly improved quality of life, mood, epilepsy self-efficacy, and epilepsy self-management. Improvements remained, at 6 months, for mood, epilepsy self-efficacy, epilepsy self-management, and medication side effect-related aspects of quality of life.

# TARGETED OUTCOMES

Participants develop coping and goal-setting strategies that improve overall and discrete aspects of quality of life, epilepsy self-management and efficacy, and alleviation of anxiety and depression.

# MEASURES AND EVALUATION ACTIVITIES

- ✓ Quality of Life (QOLIE-31)
- ✓ Epilepsy Self-Management (ESM)
- ✓ Epilepsy Self-Efficacy (ESF)
- ✓ Levels of Depression (PHQ-9) and Anxiety (GAD-7)
- ✓ Seizure Frequency
- ✓ Goal(s) Attainment

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## CURRENT EFFORTS WITH PACES

Presently, the Centers for Disease Control (CDC) is funding the University of Washington research team to expand the RCT to four epilepsy centers including the VA Puget Sound Healthcare System in order to further examine the impact of the program in multiple areas to include:

- Diverse populations of adults with epilepsy, including veterans.
- The durability of impact at a year or more across multiple areas to include seizure frequency, mood, and quality of life.
- The ability of the program to alleviate depression with the addition of Epilepsy Foundation HOPE Mentor “booster” contacts during the follow-up period (one year). Following the program’s effectiveness being established, dissemination efforts will begin nationally.
- Dissemination efforts are beginning with the support of CDC and the Epilepsy Foundation of America.



## PROGRAM COSTS

- The cost of PACES delivery will vary based upon staffing and the number of participants in a group.
- Utilizing a mental health professional (\$100-\$175 per hour) and a trained peer facilitator (\$50 per hour), the cost of the 8-week program with six participants, to include some preparation and review time, would be \$423.
- Using these figures, the cost of running a group of six would be \$2,538.
- At present, training is sponsored by the CDC at no cost.



## RESOURCE REQUIREMENTS

- Telephone conference line and toll-free number.
  - Two facilitator manuals, participant manuals, with stress reduction CDS.
- Note: Some low-income persons may need reimbursement for telephone minutes.



## TRAINING REQUIREMENTS

- Eight hours of training delivered by phone by a licensed mental health practitioner and a peer facilitator.
- The content involves 2 hours of program overview and logistics, and six hours of session content and delivery.

## REFERENCES

Fraser RT, Johnson EK, Lashley S, Barber J, Chaytor N, Miller JW, Ciechanowski P, Temkin N, Caylor L. PACES in epilepsy: Results of a self-management randomized controlled trial. *Epilepsia*. 2015 Aug;56(8):1264-74. doi: 10.1111/epi.13052. Epub



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