Cicely Saunders Institute Open Seminar Series

NOTHING ABOUT US WITHOUT US: Including people with learning disabilities
by Associate Professor Irene Tuffrey-Wijne (RN, PhD), Kingston & St. George’s University and Amanda Cresswell, Co-researcher

Wednesday 24th January 2018, 16:00-17:00
Location: Dinwoodie Lecture Theatre, Ground Floor, Cicely Saunders Institute, King’s College London, Bessemer Road, London, SE5 9PJ

The Speakers
Associate Professor Irene Tuffrey-Wijne (RN, PhD) leads a program of research focusing on intellectual disability, cancer and palliative care. She has published widely and is recognised as leading international expert in the field. Irene won the 2017 EAPC postdoctoral research award for her innovative, inclusive and ground-breaking research. Amanda Cresswell has worked with Irene for almost a decade on research around cancer, bereavement and breaking bad news. She is also a cancer survivor.

Abstract
When people with learning disabilities develop palliative care needs, the challenges for carers, professionals and service providers are enormous. This seminar will explore what it is like for people with intellectual disabilities, and their families and carers, when they reach the end of life. How can we do better – whether it is listening to their needs, or helping them understand what is happening, or assessing symptoms in people who communicate differently, or making end-of-life decisions, or finding ways to collaborate and organise services? Some of these questions need to be answered by people with intellectual disabilities themselves. This talk will demonstrate the benefits of occasionally breaking the rules of research in order to make it accessible!