Financial support for Eir Nordic is provided by Jazz Pharmaceuticals.

Eir Nordic

Eir Nordic Day

Eir Nordic Day presentations

Eir Nordic Meeting
17th October 2025
Sollentuna, Stockholm

M-NO-EPL-2500009
M-DK-EPL-2500010
M-SE-EPL-2500025
M-FI-EPL-2500002

EPILEPSI FORENINGEN
Epilepsiforbundet Dravet syndrom
Svenska Epilepsiförbundet
epilepsialiitto
Epilepsiforbundet
Jazz Pharmaceuticals

Introduction

On 17 October 2025, 50 care professionals working with people living with epilepsy and intellectual disability came together to share experiences, exchange perspectives, and discuss best practices in care.

The meeting was organised by the Nordic epilepsy organisations, with financial support from Jazz Pharmaceuticals, and aimed to recognise the individuals and organisations who go above and beyond in supporting this community.

The programme included educational presentations, best practice poster sessions, and a collaborative workshop focused on identifying opportunities for future care innovation.

This document compiles the meeting presentations.

Speakers

1 **Matilda Modigh, Annie Egelin**
With a focus on the brain, we offer an advanced-level course in epilepsy that encompasses the full care process across all levels of healthcare

2 **Marlene Linnebjerg Kudsk and Annette Frederiksen**
Network for healthcare professionals at residential facilities in Denmark

3 **Susanne Løyland**
Volunteering

4 **Anne Sabers**
Multidiciplinary care for people with developmental disabilities living in residential care homes

5 **Siv Holme Helgesen**
A Conversation Tool About Epilepsy for People with Intellectual Disabilities

01

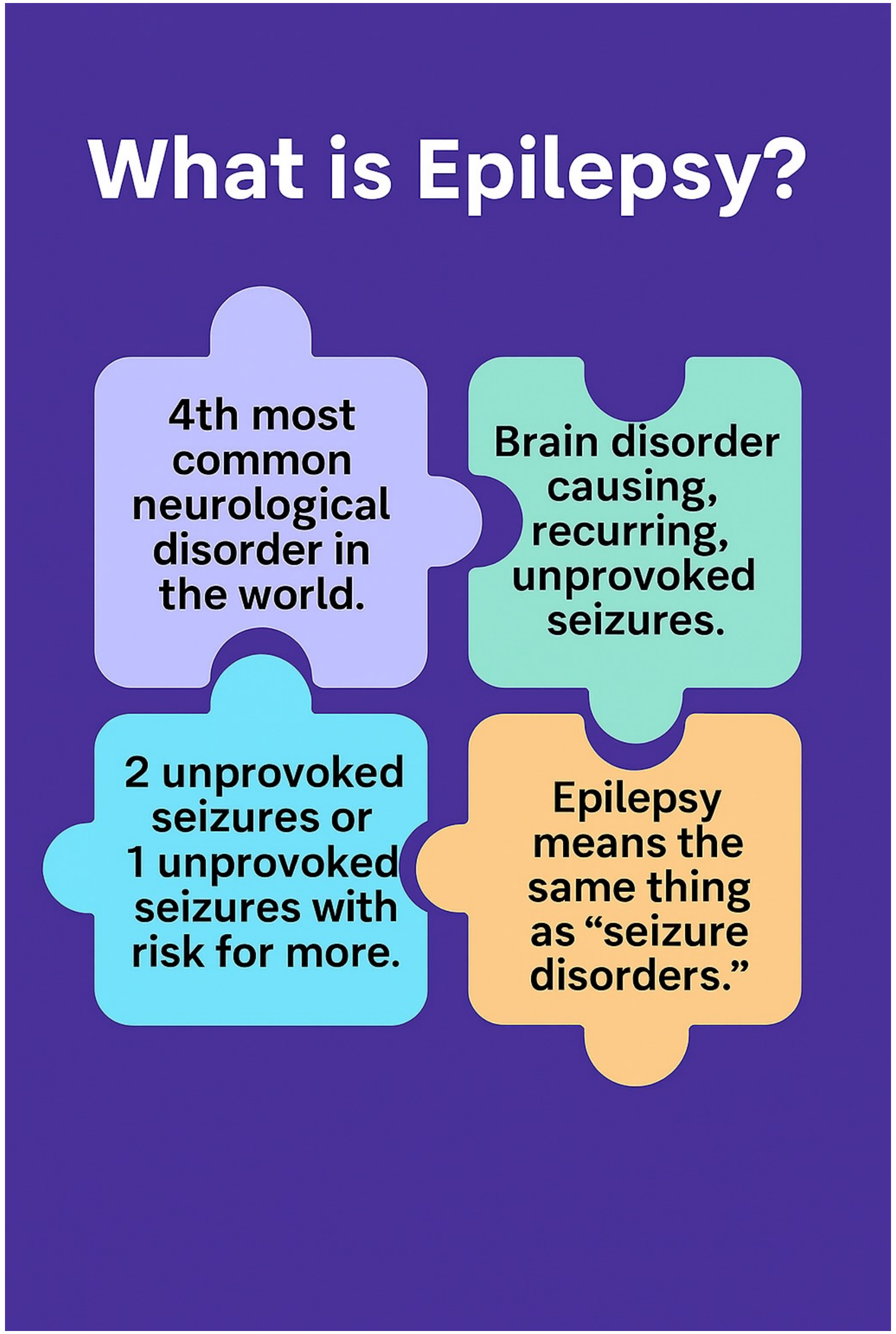
Matilda Modigh, Annie Egelin

With a focus on the brain, we offer an advanced-level course in epilepsy that encompasses the full care process across all levels of healthcare

Matilda Modigh,
Epilepsy Clinical Nurse Specialist, PhD student

Annie Egelin,
Pediatric Nurse Specialist

With a focus on the brain, we offer an advanced-level course in epilepsy that encompasses the full care process across all levels of healthcare



What is Epilepsy?

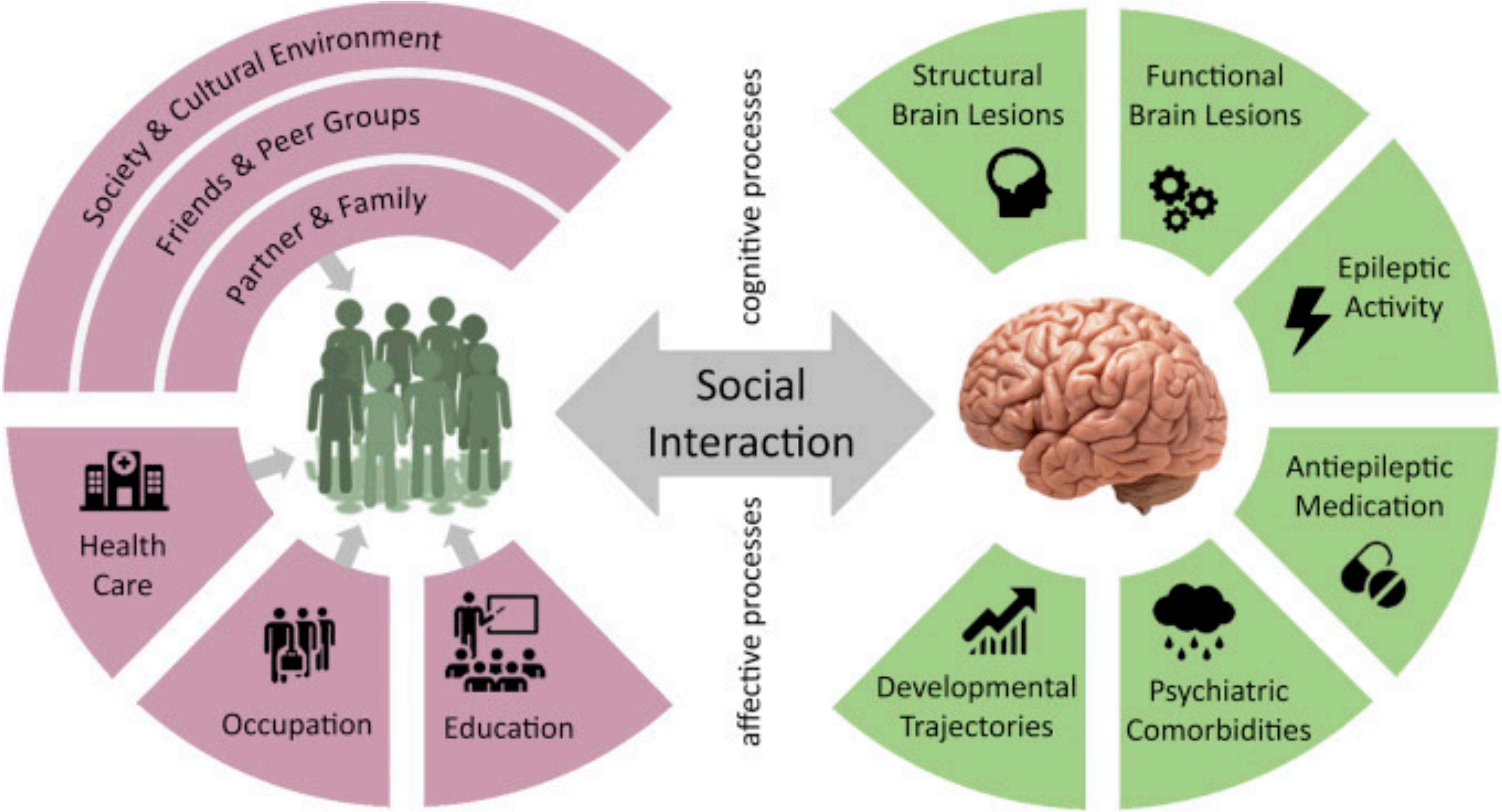
4th most common neurological disorder in the world.

Brain disorder causing, recurring, unprovoked seizures.

2 unprovoked seizures or 1 unprovoked seizures with risk for more.

Epilepsy means the same thing as “seizure disorders.”

Epilepsy Foundation, 2024.



Steiger BK, Jokeit H. Why epilepsy challenges social life. Seizure. 2017 Jan;44:194-198.

Socialstyrelsen

Nationella riktlinjer för vård vid epilepsi

Stöd för styrning och ledning

2019

SBU UTVÄRDERAR • RAPPORT 281/2018

Diagnostik och behandling av epilepsi

En systematisk översikt och utvärdering av medicinska, hälsoekonomiska, sociala och etiska aspekter

One Team – Multiple Professions – For the Patient

Increase comfort and safety

Continuity of care

Research and education

Information

Facilitates cooperation between various professions

Monitoring of treatment

Support to children with parents living with epilepsy

Transition
From pediatric care to adult care

Neurology® Clinical Practice

Research

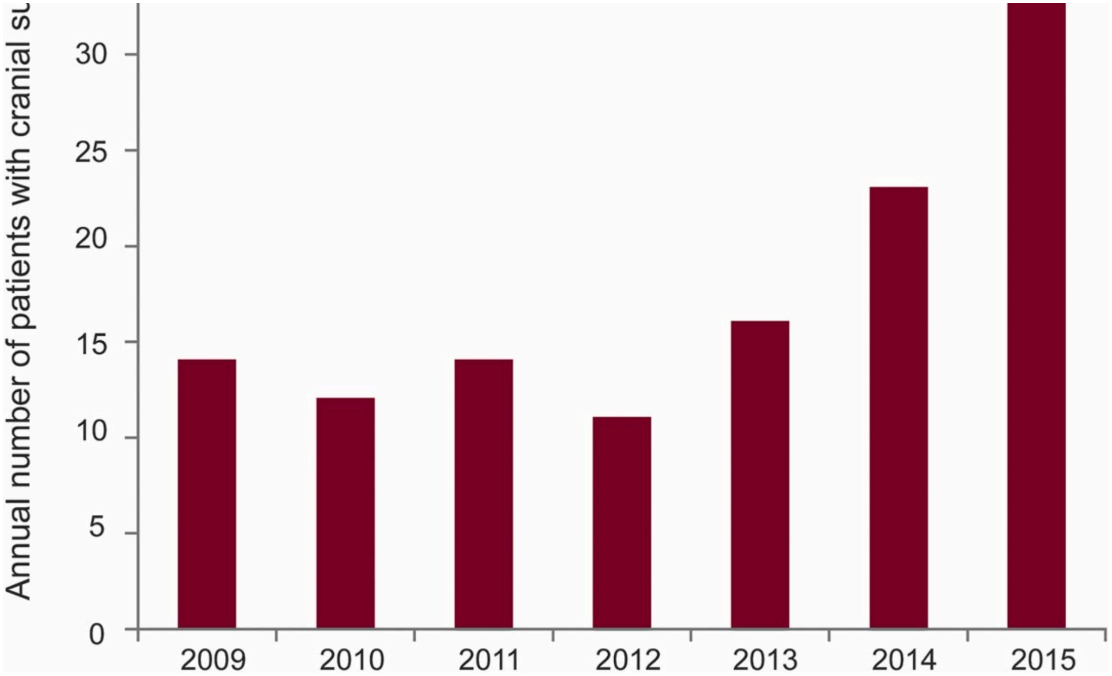
Preoperative evaluation for epilepsy surgery

Process improvement

Cornelia Drees, MD; Stefan Sillau, PhD; Mesha-Gay Brown, MD; Aviva Abosch, MD, PhD

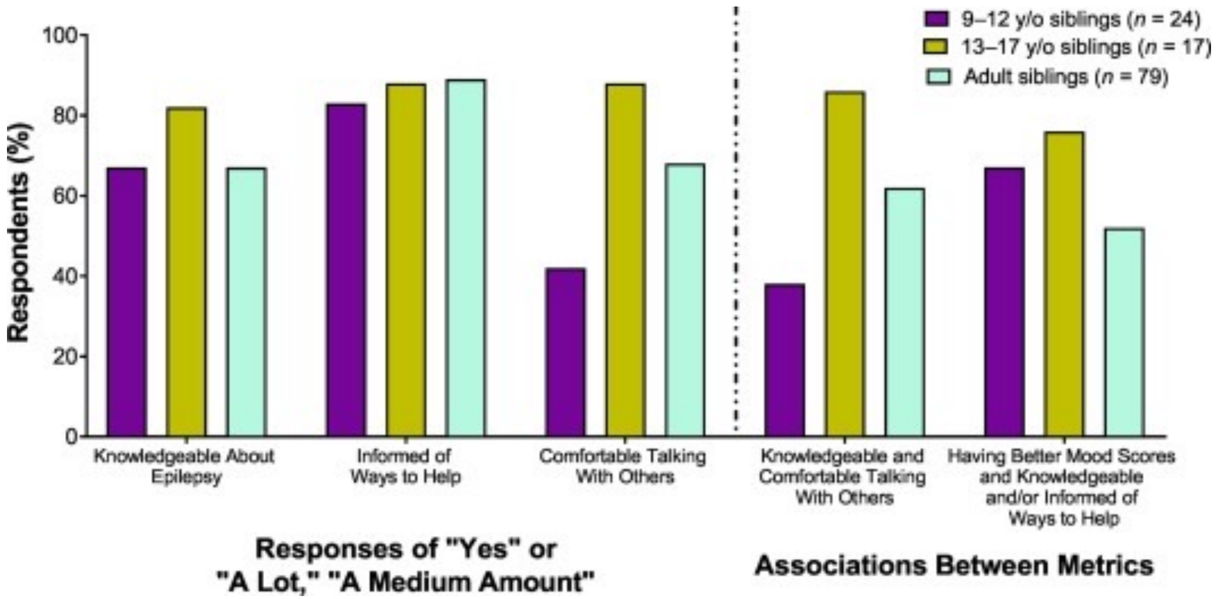
Abstract

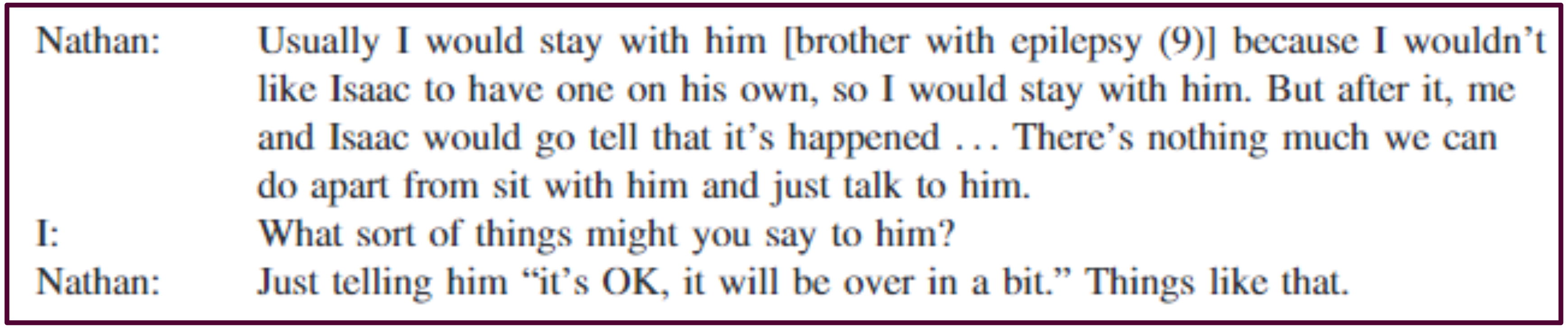
Background: Epilepsy surgery (ES) can improve seizure outcome. A prolonged duration of presurgical evaluation contributes to epilepsy-related morbidity and mortality. We introduced process changes to decrease evaluation time (ET) and increase ES numbers (excluding vagus nerve stimulation). **Methods:** The University of Colorado Hospital patient database



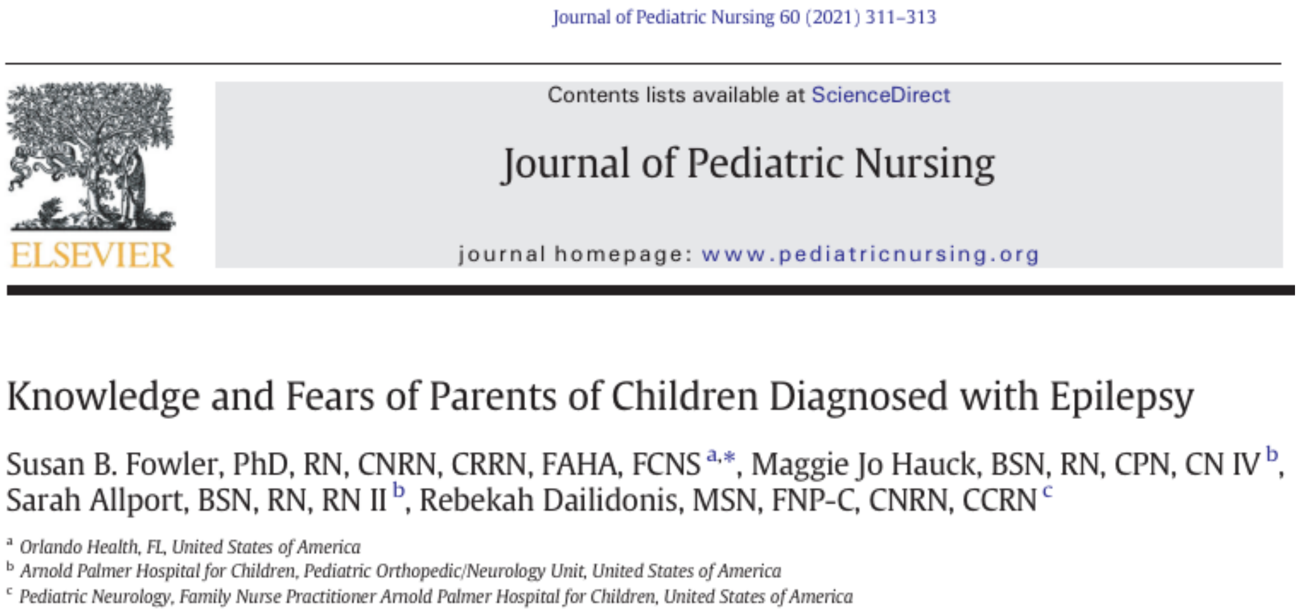
Drees, C., Sillau, S., Brown, M-G., & Abosch, A. (2017). Preoperative evaluation for epilepsy surgery. Neurol Clin Pract, 7(3), 205-213.

Baileyet al. Psychosocial impact on siblings of patients with developmental and epileptic encephalopathies. *Epilepsy Behav*. 2020;112:107377.




Nathan: Usually I would stay with him [brother with epilepsy (9)] because I wouldn't like Isaac to have one on his own, so I would stay with him. But after it, me and Isaac would go tell that it's happened . . . There's nothing much we can do apart from sit with him and just talk to him.
I: What sort of things might you say to him?
Nathan: Just telling him "it's OK, it will be over in a bit." Things like that.

Webster M. Siblings' caring roles in families with a child with epilepsy. Sociol Health Illn. 2018 Jan;40(1):204-217.



Journal of Pediatric Nursing 60 (2021) 311–313

Contents lists available at ScienceDirect

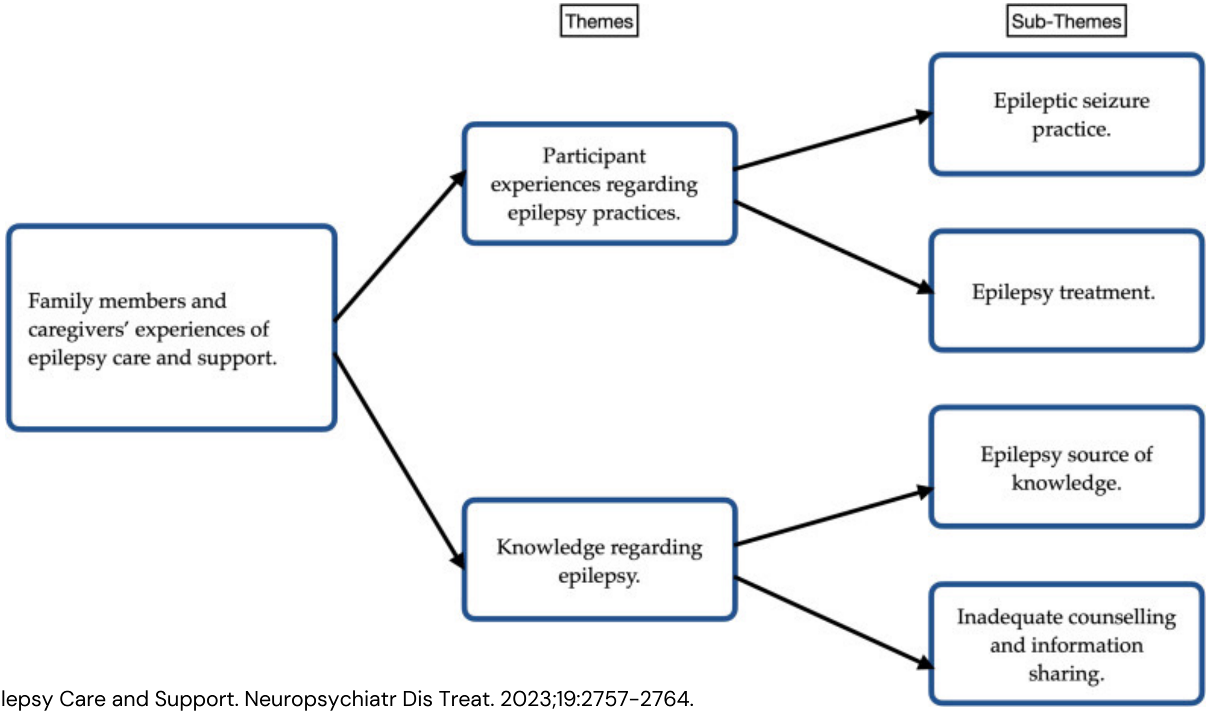
Journal of Pediatric Nursing

journal homepage: www.pediatricnursing.org

Knowledge and Fears of Parents of Children Diagnosed with Epilepsy

Susan B. Fowler, PhD, RN, CNRN, CRRN, FAHA, FCNS [a,*], Maggie Jo Hauck, BSN, RN, CPN, CN IV [b], Sarah Allport, BSN, RN, RN II [b], Rebekah Dailidonis, MSN, FNP-C, CNRN, CCRN [c]

[a] *Orlando Health, FL, United States of America*
[b] *Arnold Palmer Hospital for Children, Pediatric Orthopedic/Neurology Unit, United States of America*
[c] *Pediatric Neurology, Family Nurse Practitioner Arnold Palmer Hospital for Children, United States of America*



Themes

Sub-Themes

Family members and caregivers' experiences of epilepsy care and support.

Participant experiences regarding epilepsy practices.

Knowledge regarding epilepsy.

Epileptic seizure practice.

Epilepsy treatment.

Epilepsy source of knowledge.

Inadequate counselling and information sharing.

Musekwa OP, Makhado L. It Goes Beyond Anxiety: Experiences of Family Members and Caregivers of Epilepsy Care and Support. Neuropsychiatr Dis Treat. 2023;19:2757-2764.

Knowledge

Experiences

Pedagogy

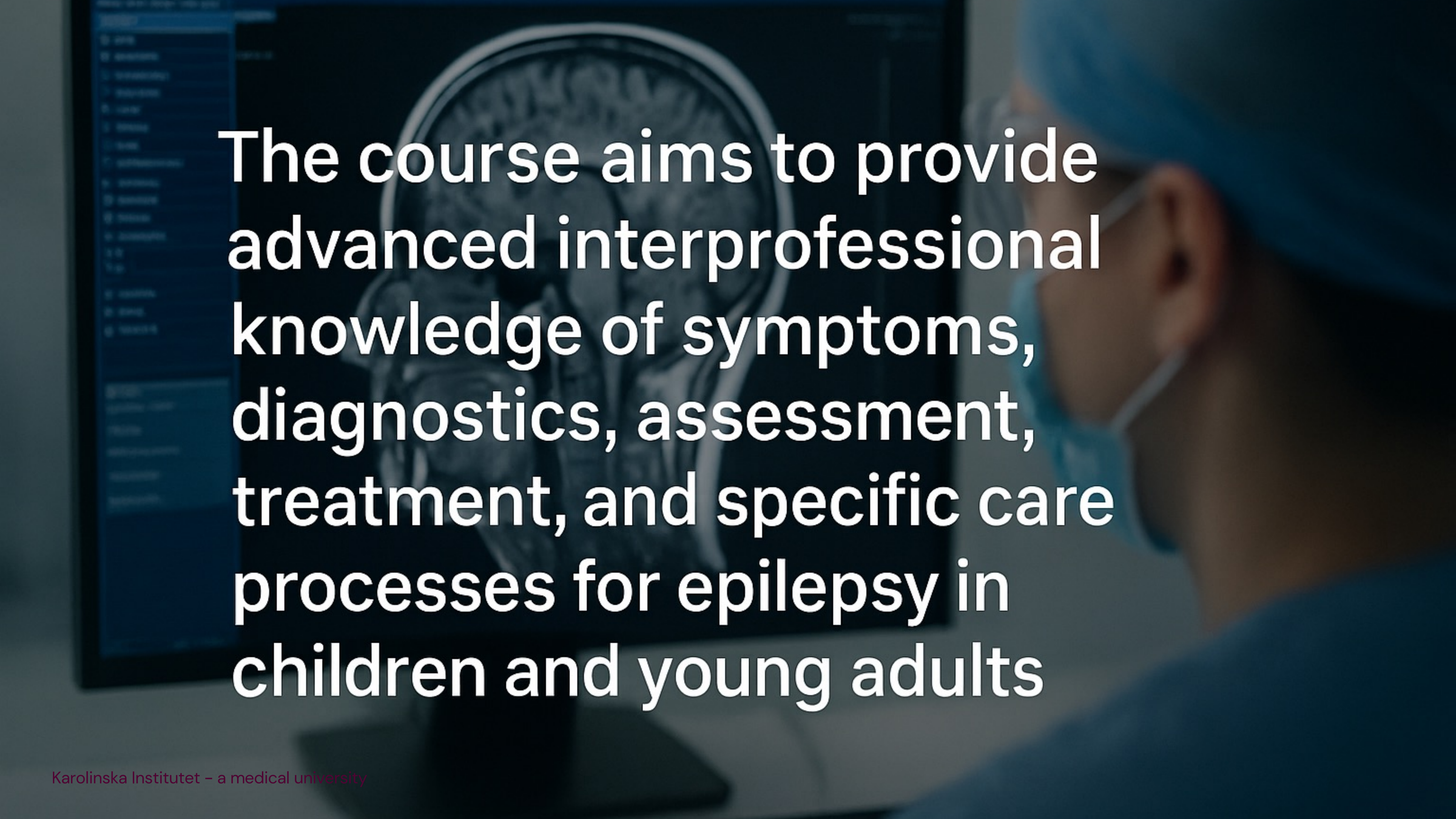
Collaboration

Holistic approach

/ Uppdragsutbildning/ Kursutbud/ Epilepsi - med fokus på barn och unga vuxna, VT 2026

Epilepsi - med fokus på barn och unga vuxna, VT 2026

Epilepsi är en specialitet i ständig utveckling som omfattar en komplexitet med komorbiditet och stora patientgrupper. Ungefär 81 000 barn och vuxna lever med epilepsi och övergången från barnsjukvård till vuxensjukvård innebär ett behov av stor kompetens hos professioner för att kunna bedriva en god och säker vård.



The course aims to provide advanced interprofessional knowledge of symptoms, diagnostics, assessment, treatment, and specific care processes for epilepsy in children and young adults

Designed for nurses and other healthcare professionals

Provides advanced knowledge of symptoms, diagnostics, treatment, and care processes

Enhances interprofessional collaboration

Nurses

Medical Laboratory Technologist

Dietitian

Neuropsychologist

Assistant nurses

45 students who have completed the course

thank you!

Please feel free to send an e-mail if you have any questions

matilda.modigh@ki.se
annie.egelin@regionstockholm.se

02

Marlene Linnebjerg Kudsk and Annette Frederiksen

Network for healthcare professionals at residential facilities in Denmark

Financial support for Eir Nordic is provided by Jazz Pharmaceuticals.

Eir Nordic

Eir Nordic Day

Network for healthcare professionals at residential facilities in Denmark

Marlene Linnebjerg Kudsk
Annette Frederiksen


Not an actual patient

EPILEPSI FORENINGEN

Epilepsiforbundet
Dravet syndrom

Svenska Epilepsiförbundet

epilepsialiitto

Epilepsiforbundet

Jazz Pharmaceuticals

Disclaimer

No conflict of interest. The presentation has been prepared independently of and without influence from the meeting organizer Jazz Pharma

epilepsi
netværket
et vidensnetværk
for bosteder

The Epilepsy Network

– a professional knowledge network for care homes

epilepsi netværket
et vidensnetværk for bosteder

- A network for healthcare professionals working in care homes – caring for people living with epilepsy
- Focused on Denmark
- Marlene Linnebjerg Kudsk – Healthcare consultant, network coordinator
- Annette Frederiksen – Nurse, network coordinator

Background and context

The Danish Health Authority's 2018 inspection report suggested 2 focus areas:

- *Healthcare competencies at residential facilities:* Municipalities must ensure that residential facilities have staff with relevant healthcare competencies who can manage medication, administer acute anti-seizure medicine, handle and recognize seizures, as well as carry out observation and registration of seizures. This is important so that the responsible doctor can plan the medical treatment.
- *Dissemination of knowledge about epilepsy:* Municipalities must ensure, in collaboration with the regions, patient associations, and the specialized municipal and regional services and knowledge environments, that the necessary healthcare knowledge is made available to and disseminated among professional and authority personnel in the municipalities across administrative and professional areas.

Epilepsy treatment efforts in Denmark

- In 2019, the Finance Act allocated DKK 32.3 million to the following epilepsy initiatives:
  - National treatment and referral guidelines.
  - Recommendations for cross-sectoral care pathways.
  - Dissemination of epilepsy knowledge in municipalities.
  - Solutions for transition from child → youth → adult.
  - Multidisciplinary functional assessments and rehabilitation.

In the evaluation of these initiatives, Defactum (a research and consulting organization) notes:

It should be considered going forward how to ensure access to healthcare knowledge about epilepsy in residential facilities for people with both intellectual disabilities and epilepsy, where the need for knowledge and treatment is significant.

Footnote nunc pellentesque bibendum porttitorr

Purpose

A network for healthcare professionals working at children's and youth residential facilities has been established as a resource network and a space for sparring amongst professionals with vested interest in epilepsy.

The network is a professional, ethical, and practical network.

The purpose is, among other things, to support the development of initiatives and to focus on epilepsy among residents of all ages in both day and residential facilities.

It also aims to create greater security for employees and relatives – for the benefit of the residents.

We do this by:

Inspire and share knowledge across day and residential facilities in Denmark.

Gain greater knowledge and improve the handling of epilepsy among residents in care facilities, including observation and documentation as a basis for better follow-up and treatment.

Develop a network that can inspire education and guidance for staff, residents, and relatives.

Support collaboration between the healthcare system, staff, and relatives.

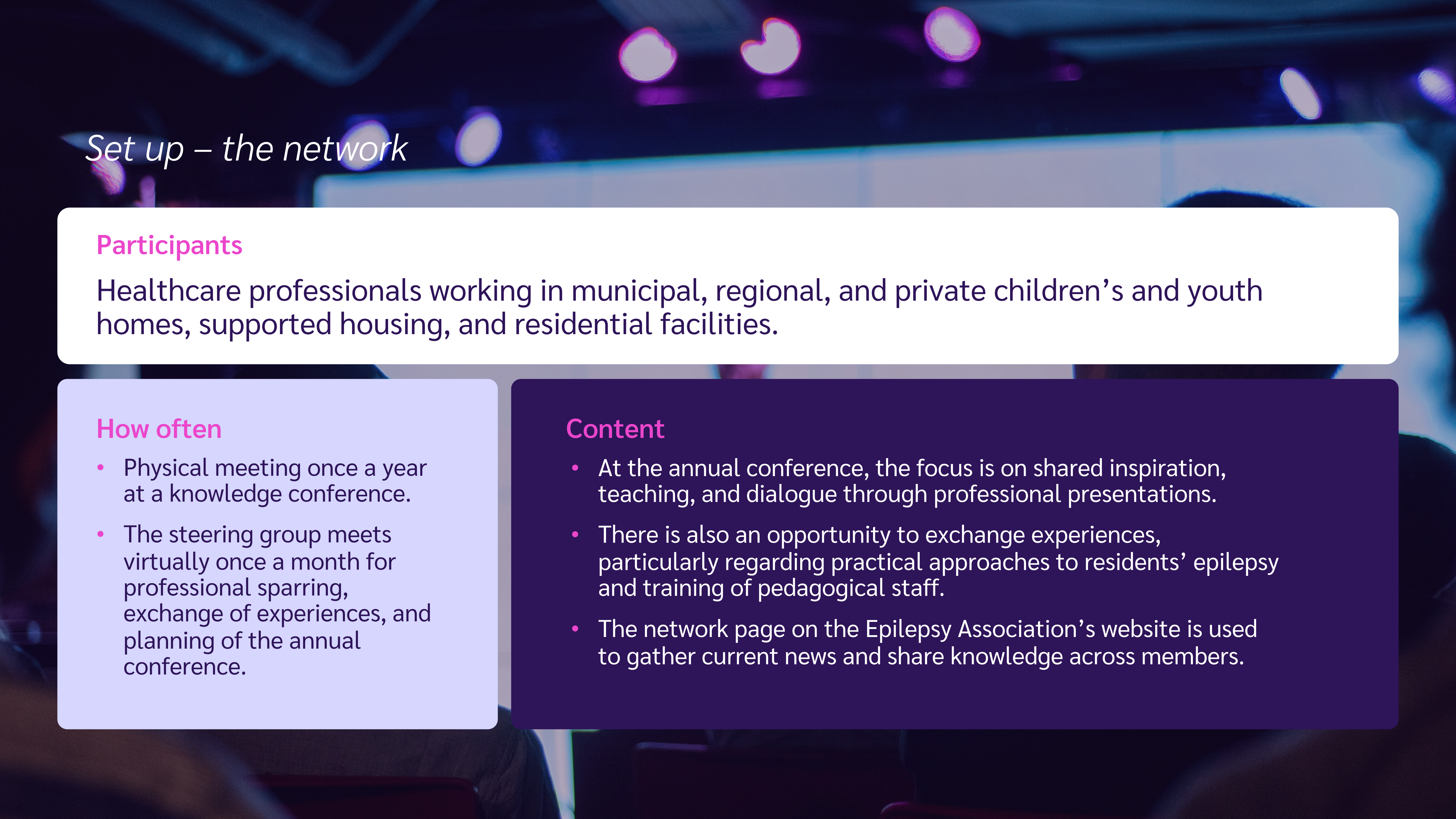
Create more knowledge and security among staff in their daily work with residents who have epilepsy.

Improve the management of healthcare knowledge in the field.

Focus on the living conditions of people with epilepsy.

Establish a knowledge portal for healthcare employees who are new to the field and need access to specialized knowledge and networks.

Use the network for ongoing collection and focus on specific issues, and for the implementation/development of good solutions for the target group – based on "current best knowledge" and research in the field.



Set up – the network

Participants

Healthcare professionals working in municipal, regional, and private children's and youth homes, supported housing, and residential facilities.

How often

- Physical meeting once a year at a knowledge conference.
- The steering group meets virtually once a month for professional sparring, exchange of experiences, and planning of the annual conference.

Content

- At the annual conference, the focus is on shared inspiration, teaching, and dialogue through professional presentations.
- There is also an opportunity to exchange experiences, particularly regarding practical approaches to residents' epilepsy and training of pedagogical staff.
- The network page on the Epilepsy Association's website is used to gather current news and share knowledge across members.

Resources and support

- The network has a site under the Epilepsy Association’s website.
- The Epilepsy Association provides practical support, including the member page and the execution of the annual conference.
- We seek sponsorships from pharmaceutical companies for the annual conference.
- Primarily interest hours/voluntary work from coordinators and steering group members




Evaluation of the network's progress so far

- Greater focus on and knowledge about epilepsy at residential facilities.
- Strong participation in the network and conferences shows interest and a need for more knowledge.
- Currently 330 members in the network and 150 participants at each conference in 2023 – 2024 – 2025.
- Through the network, we are involved in various dialogue meetings on epilepsy among people in residential facilities and with disabilities.

Reflections and advice

It takes dedicated people

Good collaboration with professional partners is essential, including the Epilepsy Association, pharmaceutical companies, etc.

It is difficult to keep the network page active – everyone has a busy everyday life.

Success brings influence

It requires perseverance

Eir Nordic

03

Susanne Løyland

Volunteering

Ein Nordic

Volunteering

Susanne Løyland

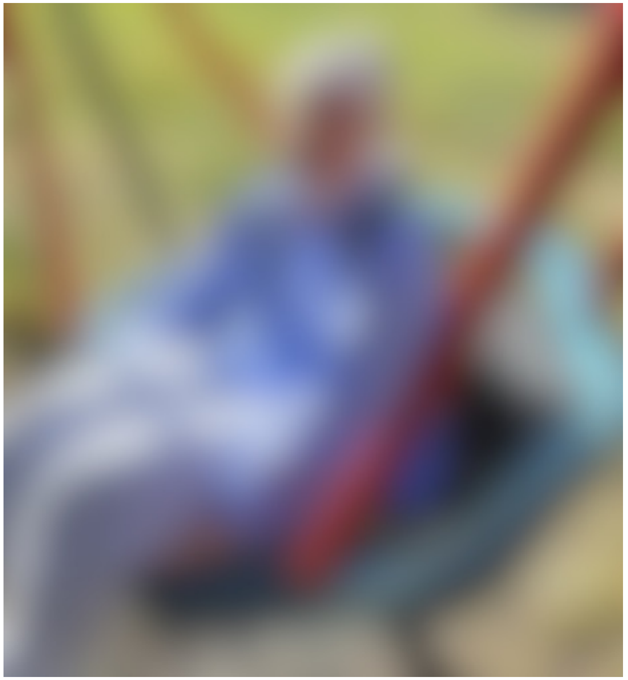
Chairman Epilepsy Association Dravet syndrom
Norway

Eir Nordic Day 17.10.25

Epilepsiforbundet
Dravet syndrom

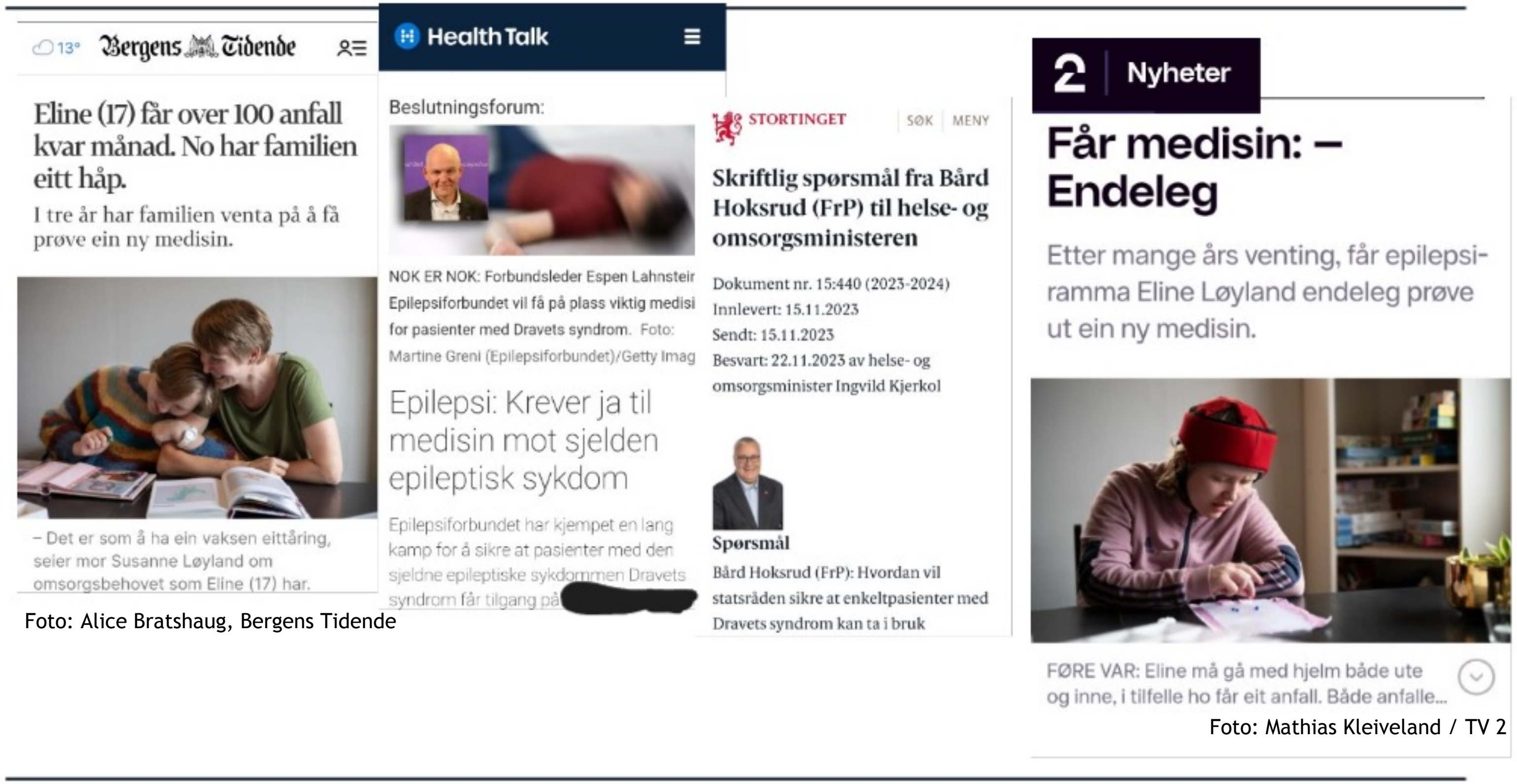
What is volunteering?

- to make a difference and support families affected by epilepsy, and Dravet syndrome in particular
- to spread information about Dravet syndrome
- to engage in interest-based political work that is important for families with the diagnosis
- to work on behalf of the group, for all those who do not have the opportunity and strength themselves, to work towards good for the community



Why did I start volunteering?

- Daughter 19 years old, diagnosed with Dravet syndrome at 4 years old
- Dravet syndrome is a rare and catastrophically developmental and epileptic encephalopathy.
- Missed a place to belong
- Wanted to create a place for families affected by the diagnosis, and especially newly diagnosed



Eline (17) får over 100 anfall kvar månad. No har familien eitt håp.

I tre år har familien venta på å få prøve ein ny medisin.

– Det er som å ha ein vaksen eittåring, seier mor Susanne Løyland om omsorgsbehovet som Eline (17) har.

Foto: Alice Bratshaug, Bergens Tidende

Beslutningsforum:

NOK ER NOK: Forbundsleder Espen Lahnstein Epilepsiforbundet vil få på plass viktig medisi for pasienter med Dravets syndrom. Foto: Martine Greni (Epilepsiforbundet)/Getty Imag

Epilepsi: Krever ja til medisin mot sjelden epileptisk sykdom

Epilepsiforbundet har kjempet en lang kamp for å sikre at pasienter med den sjeldne epileptiske sykdommen Dravets syndrom får tilgang på [redacted]

Skriftlig spørsmål fra Bård Hoksrud (FrP) til helse- og omsorgsministeren

Dokument nr. 15:440 (2023-2024)
Innlevert: 15.11.2023
Sendt: 15.11.2023
Besvart: 22.11.2023 av helse- og omsorgsminister Ingvild Kjerkol

Spørsmål

Bård Hoksrud (FrP): Hvordan vil statsråden sikre at enkeltpasienter med Dravets syndrom kan ta i bruk

Får medisin: – Endeleg

Etter mange års venting, får epilepsiramma Eline Løyland endeleg prøve ut ein ny medisin.

FØRE VAR: Eline må gå med hjelm både ute og inne, i tilfelle ho får eit anfall. Både anfalle...

Foto: Mathias Kleiveland / TV 2

We chose to share our story in local and national media to give the issue about new treatments in Norway a personal touch . Just to be able to help all those who had an unsustainable everyday life and were just waiting for new treatment options.

Epilepsiforbundet Dravet syndrom:

- a board of 4 members.
- guidance and support for families through conversations, both in person, by phone or digitally.
- digital meetings once a month for parents/realtives.
- Whatsapp group for parents/relatives.
- family gatherings, the next one in June 2026.
- organized a gathering for parents/relatives last month.
- collaborate with both national and international organizations.
- participating in conferences/webinars.

Where to find us:

www.dravet.no (www.epilepsi.no/dravet)

dravet@epilepsi.no

https://www.facebook.com/dravet.no

Instagram: dravetsyndrom

Reflections and advice:

- encourage families to contact voluntary patient organisations for support and advice
- volunteering offers personal growth and builds a strong social community through meaningful contributions.
- even small contributions in volunteering help build a more inclusive, knowledgeable society benefiting all

Together we are stronger and we can make a difference!

Thank you very much for your attention!

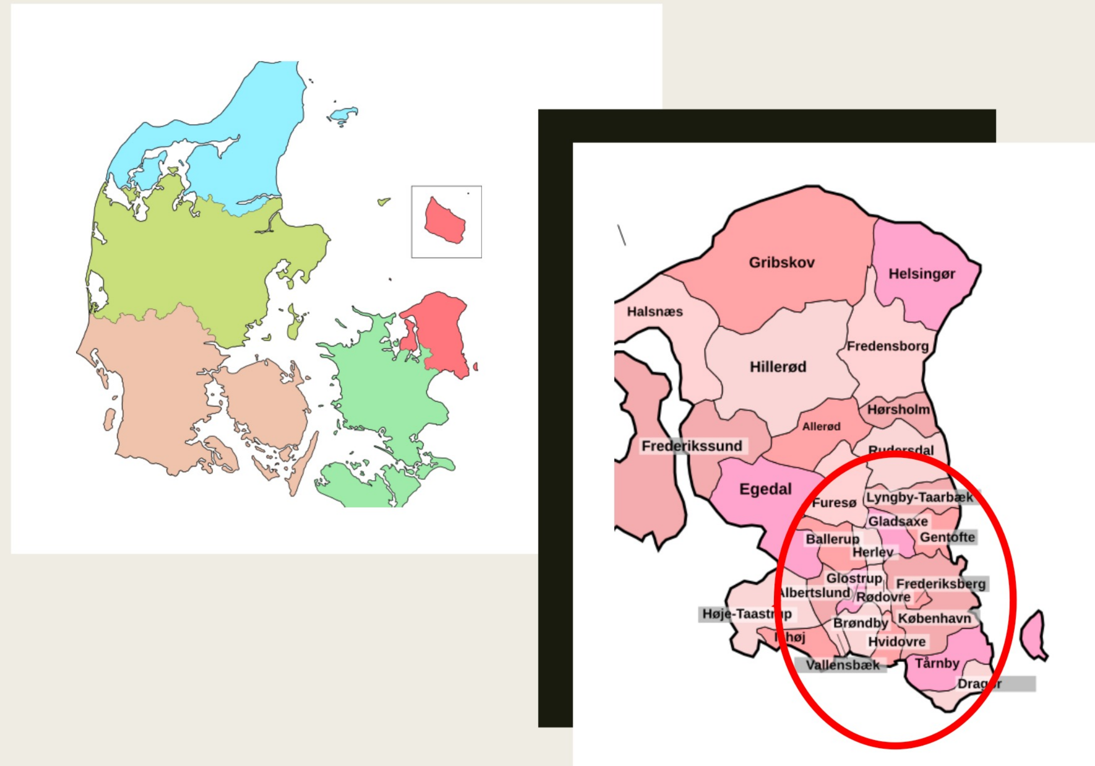
Rigshospitalet

The Capital Region, Copenhagen Denmark.

Multidiciplinary care for people with developmental disabilities living in residential care homes

Anne Sabers, MD, DMSc,
Adult neurologist,
epileptologist

The Epilepsy Clinic
Rigshospitalet Copenhagen
University Hospital



04

Anne Sabers

Multidiciplinary care for people with developmental disabilities living in residential care homes

Ein Nordic

THE ISSUE

PERSONS WITH DEVELOPMENTAL DISABILITIES:

EXPERIENCING A WIDE RANGE Of HEALTH PROBLEMS

- Physically
- Mentally

DO NOT RECEIVE THE SAME STANDARD OF MEDICAL CARE AS OTHERS

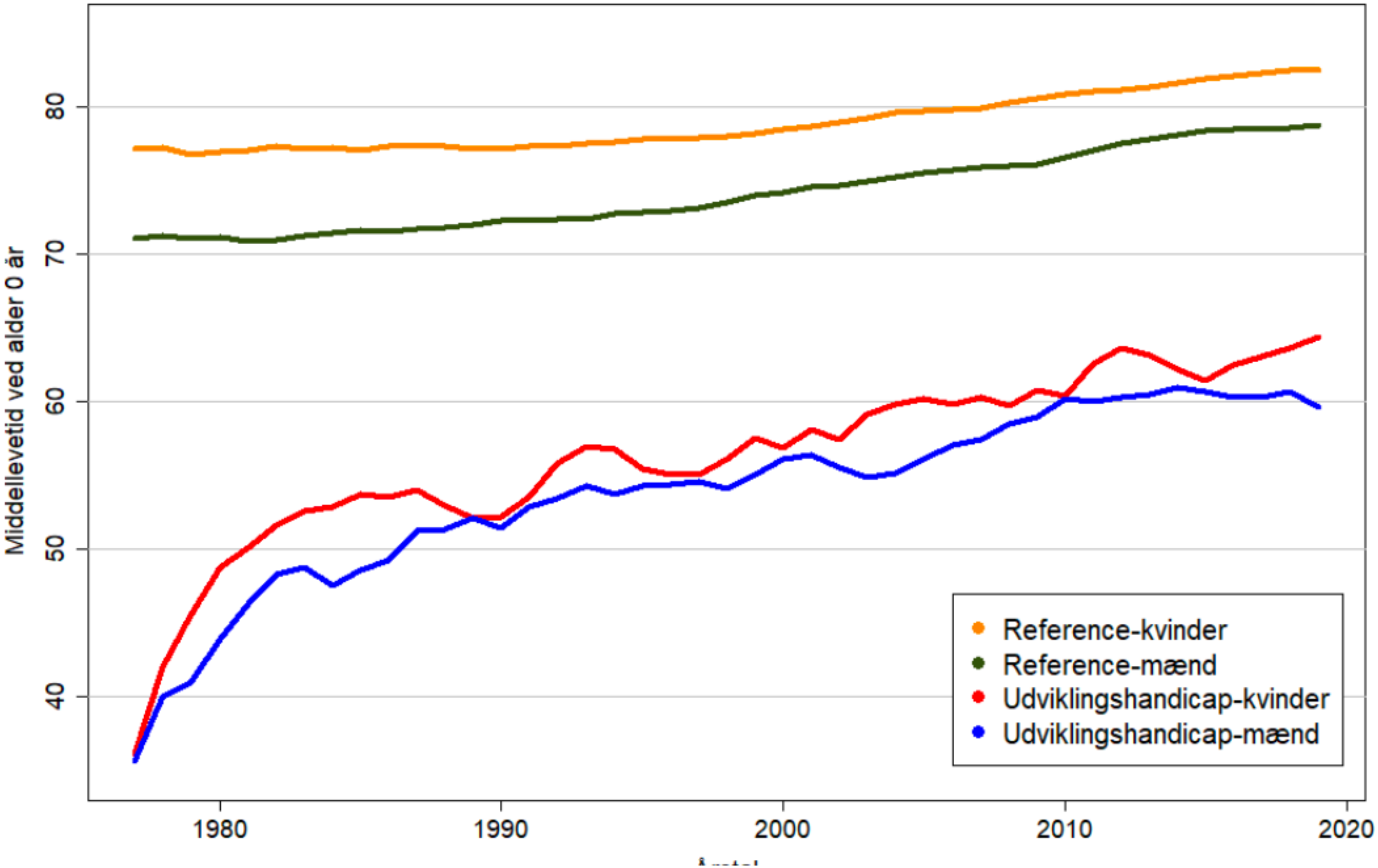
- Increased mortality

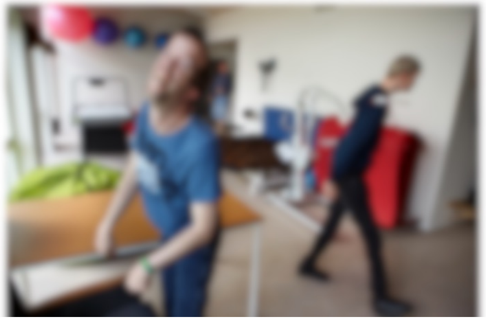
”OVERSHADOWING”

- Symptoms are mistakenly attributed to the disability

Healthcare promotion activities in with intellectual disability are insufficient

Figur 3. Middellevetid ved alder 0 år for personer med udviklingshandicap og referencepopulationen fra 1976 til 2020 opdelt på køn






Statens Institut for Folkesundhed

Dødelighed blandt personer med udviklingshandicap

Susan Ishøy Michelsen
Tina Harmer Lassen
Trine Allerslev Horsbøl
Isabelle Pascale Mairey
Knud Juel
Lau Caspar Thygesen

SDU

SDU

Dødelighed blandt 18-74-årige med udviklingshandicap

Fokus p

Lau Caspar
Marie Borrin
Knud Juel
Susan Ishøy

Syddansk Universitet
Statens Institut for Folkesundhed

European Journal of Public Health, 2024, ckae118

https://doi.org/10.1093/eurpub/ckae118

Potentially avoidable mortality among adults with intellectual disability

Lau Caspar Thygesen [1,*], Marie Borring Klitgaard [1], Anne Sabers [2], Jakob Kjellberg [3], Jens Søndergaard [4], Jeppe Sørensen [5], Marie Sonne [6], Knud Juel [1], Susan Ishøy Michelsen [1]

[1] National Institute of Public Health, University of Southern Denmark, Copenhagen, Denmark
[2] The Epilepsy Clinic, Department of Neurology, Rigshospital University Hospital, Copenhagen, Denmark
[3] VIVE—The Danish Center for Social Science Research, Copenhagen, Denmark
[4] The Research Unit for General Practice, Department of Public Health, University of Southern Denmark, Odense, Denmark
[5] Lev—Inclusion Denmark, Høje-Taastrup, Denmark
[6] Social Pedagogues National Association, Copenhagen, Denmark

PERSONS WITH DEVELOPMENTAL DISABILITIES FACE CHALLENGES IN EVERYDAY LIVES BY:

COMMUNICATION – understanding and expressing needs can be limited -

- DEPENDENT on carer / family

COORPORATION – limited ability to follow social rules and reflection

- UNDER- and MISDIAGNOSIS and INSUFFICIENT treatment

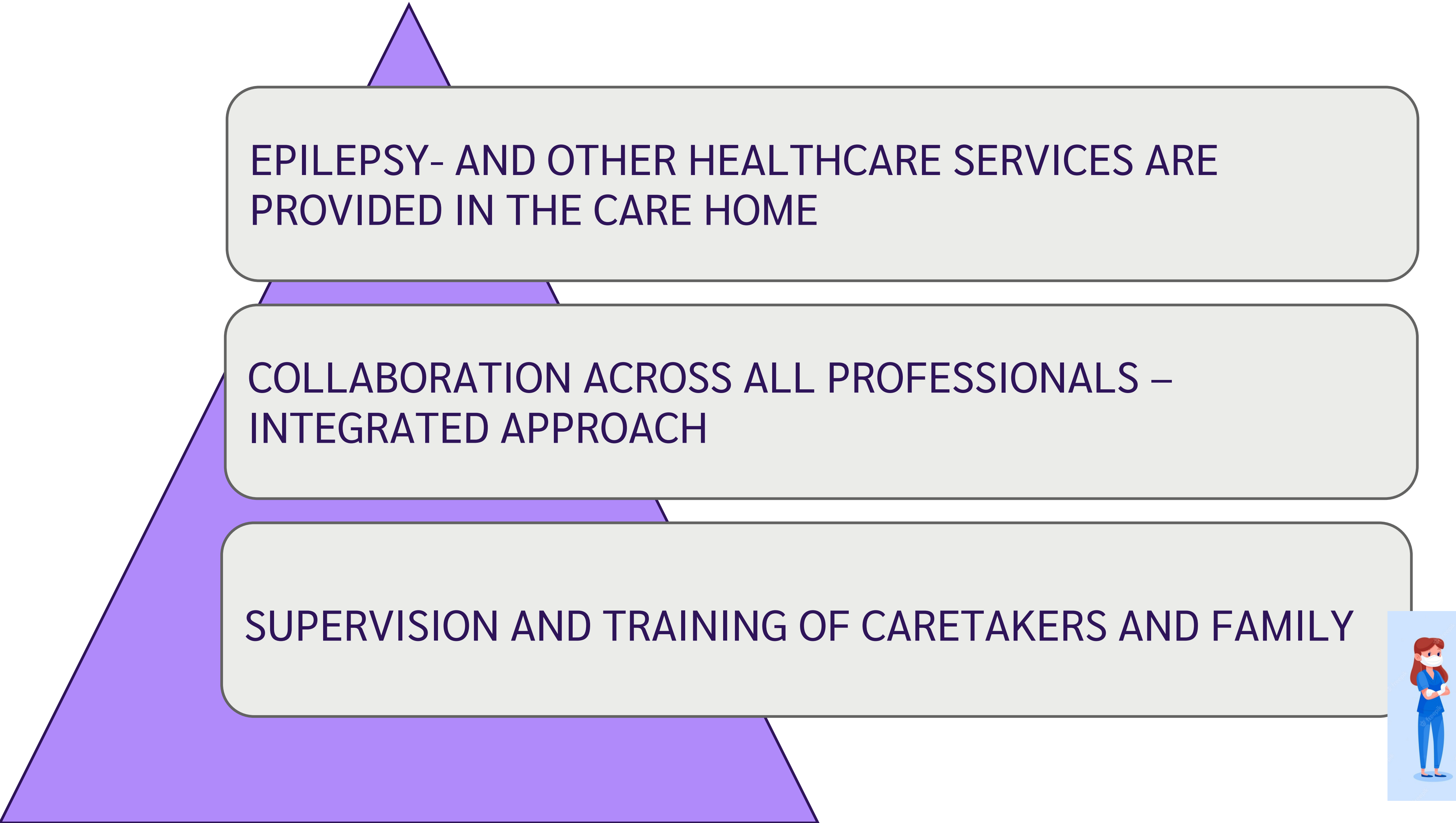
MULTIMORBIDITY

- Many healthcare contacts / professionals involved
- Polyfarmacy

Rigshospitalet

THE ACTIVITY

PERSONS WITH DEVELOPMENTAL DISABILITIES:



EPILEPSY- AND OTHER HEALTHCARE SERVICES ARE PROVIDED IN THE CARE HOME

COLLABORATION ACROSS ALL PROFESSIONALS – INTEGRATED APPROACH

SUPERVISION AND TRAINING OF CARETAKERS AND FAMILY

REGION H Rigshospitalet

THE MULTICIPLINARY TEAM

EPILEPSY SERVICE RIGSHOSPITALET, DENMARK

SHARED CARE

LOCAL SERVICE – WITH CARERS AND FAMILY IN THE CARE HOME – and HOTLINE

Neurologist and nurse from epilepsy clinic

MULTIDICIPLINARY CONFERENCES

Psychiatrist, geneticist, (general practitioner)

SUPERVISION AND EDUCATION

Caretakers and family

OUTCOME AND RESULTS

IMPROVED SERVICE AND A REDUCED OVERALL DISEASE BURDEN

REDUCED MISSED APPOINTMENTS

REDUCTION IN ACUTE HOSPITALISATIONS

RESOURCE, REFLECTION AND ADVICE

RESOURCES ARE UTILIZED MORE EFFICIENTLY – CAN BE PARTLY DIGITALLY

Depending on the local conditions and circumstances – Logistical factors and sufficient patient population

MAY CONTRIBUTE TO INCREASED JOB SATISFACTION

Better knowledge and control may reduce stress level and improved staff retention among caregivers

WORKING ACROSS DISCIPLINES SUPPORTS DEVELOPMENT AND RESEARCH

Contributing to higher quality in patient care

Eir Nordic

Thank you!

05

Siv Holme Helgesen

A Conversation Tool About Epilepsy for People with Intellectual Disabilities

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Eir Nordic Day

A Conversation Tool About Epilepsy for People with Intellectual Disabilities

Siv Holme Helgesen
Moss, Norway

EPILEPSI FORENINGEN
Epilepsiforbundet Dravet syndrom
Svenska Epilepsiförbundet
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Epilepsiforbundet
Jazz Pharmaceuticals

A conversation tool (booklet + support pictures)

Focus on four topics: Brain – Seizures – Health – Hospital

Used together with a caregiver/service provider

***AIM:** Increase knowledge about own epilepsy*

Background and context

- People with intellectual disabilities = lower health literacy
- Many also have epilepsy → often poor understanding of diagnosis
- Lack of existing Norwegian tools for adults
- Inspired by existing tools (KIS, Body Cards, Episnakk for children)

Key steps / how it works

- Based on Model for Quality Improvement
- Development in cooperation with SSE (Special Hospital for Epilepsy)
- Pilot tested with one adult user + caregiver
- Evaluation with both caregiver and user

Not an actual patient

Resources and tools

- Conversation tool (landscape page: text + picture)
- Training/guidance for staff
- Collaboration with SSE and local services
- Evaluation forms (staff + smiley scale for participant)
- Networking to reach more participants

Hjernen

Visste du at hjernen er sjefen i kroppen? Den styrer tankene dine, følelsene dine, og alt du gjør.

Hjernen ligger inne i hodet. Den er beskyttet av hodeskallen. På bilde ser du hjernen og hva den gjør (vis og pek på bildet).

Sanser

Hjernen tar imot beskjeder fra kroppen. Den får beskjeder fra øynene, ørene, munnen og huden.

- Øynene forteller hva du ser
- Ørene forteller hva du hører
- Munnen smaker maten du spiser
- Huden kjenner om noe er kaldt eller mykt
- Nesen kjenner lukter

Beskjedene du får fra kroppen hjelper hjernen med å forstå verden. Når du ser en katt og kjenner på den myke pelsen, sier hjernen: "Det er en katt!".

Støttebilde (fra Eisai):

Thank you!

Eir Nordic