

# United in HOPE

## 2025 PWS CONFERENCE

 **Prader-Willi**  
SYNDROME ASSOCIATION | USA  
SAVING AND TRANSFORMING LIVES

 **IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

 **FOUNDATION FOR  
PRADER-WILLI  
RESEARCH**



# FAMCARE

**Verena Gutmann - Austria**

**Georgina Loughnan - Australia**



# Welcome

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4 weeks

## FAMCARE's mission

Education and support **for** parents, family members, carers, persons dealing with people living with PWS **from** parents and experts well-experienced with PWS – all over the world.

Thank you for your attention!



34 years

# History of FAMCARE Care for families

## 2012 – Survey

127 adults completed

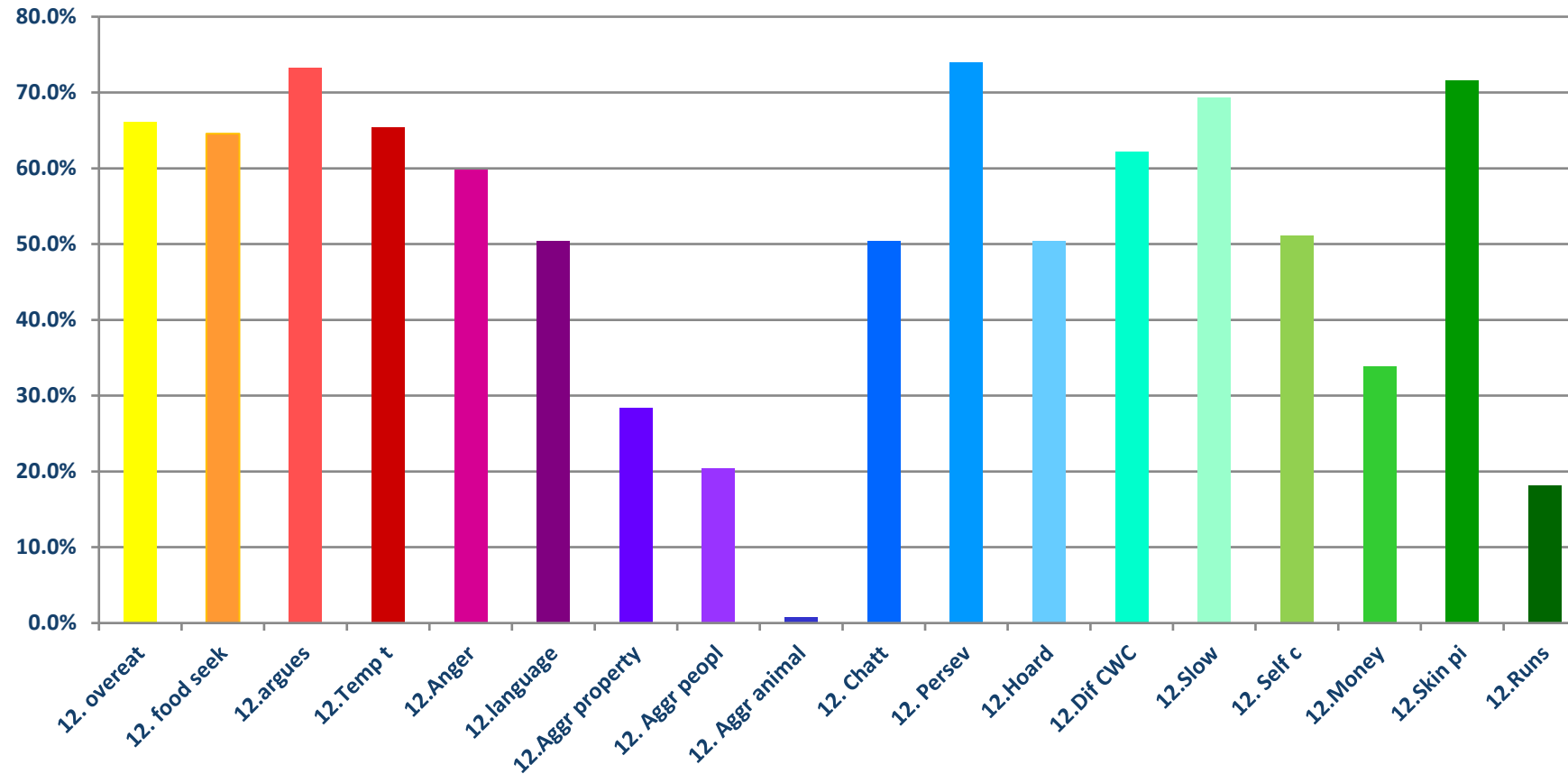
27.5 yrs mean age of person with PWS

50% female

73.2% lived with both parents



# PWS traits seen in 127 adults





# Most Stressful PWS Traits

Food related

Anger

Arguments

Temper tantrums

Inability to cope with change

Skin picking

Perseveration



Excessive Talking

# Families' Desires

Residential services

Professional information & advice

Education from other parents

Availability of PWS knowledgeable professionals

Job / activity centres

Respite centres

Support for families

Improved societal & government awareness of PWS

???



Nutrition Workshop



BIRD Institute - PWS diagnostic laboratory Italy

# Successful Strategies

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None

Threaten / punish with food / train to feel full

Prepare for change

Lock food

Routine

Positive behaviour management

Talking & reasoning

Firmness / no arguing

Ignore behaviour → talk later

Remain patient & calm

# Structure

2025

## Famcare Committee

7 people from 7 countries

## Famcare Advisory Board

3 people from 3 countries

Amalia Balart – Chile

Jackie Gill - UK

Lesley Robertson - Australia

## IPWSO Board



## FAMCARE Board

6 PWS mothers + Georgina as specialist and Susanne with both qualities



Chair: **Verena Gutmann**  
Austria, Since Jan 2020



**Dr. Susanne Blichfeldt**  
Denmark  
founder member



**Karin Clarke**  
South Africa  
Since June 2023



**Maria Elvira Garcia**  
Colombia  
Since Oct 2020



**Georgina Loughnan**  
AUS  
FAMCARE founder



**Liane Motta**  
Brazil  
Since May 2025



**Karen O'Reilly**  
New Zealand  
Since December 2024

May 2025



# Topics

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- Coping with Change
- Duty of Care
- Exercise
- Health Checklist
- Healthy Adult Life
- I Want the Same
- Law Enforcement Matters
- Life Plan
- Managing a Meltdown
- Motivation
- Personal Care
- Preparing for When Parents are Gone
- Promoting Positive Behaviour Throughout Life
- PWS Awareness for Professionals
- Skin Picking
- Story Telling
- Strength in Boundaries
- Support Through COVID19
- The Importance of Planned Purposeful Days
- Too Hot Too Cold
- Transitional Years
- When Rituals Become a Problem

# Coping with Change

## ISSUES

“Fear” of change or something new

Desire routine and known schedule

Difficulty switching attention



## STRATEGIES

- Planning, do so thoroughly and check all details
- Always have a Plan B – pre discussed
- Give choice (appropriate and deliverable) where possible
- Pre agreement on boundaries during outings
- Use visuals
- Remain calm & patient, but direct
- Involve in problem solving
- Ask for their assistance
- Give a solution before explaining the need for change
- Praise for accepting required change

# Duty of Care



## ISSUES

Support is lifelong

Support is specific & different

Duty of Care means providing the “best” of...

Societal rights

Legal rights

Personal preferences if possible

## STRATEGIES

- Seek expert PWS knowledge
- Do not hold back in sharing PWS knowledge
- Reinforce the different needs and abilities of someone with PWS – *differently abled*
- Teach others about your *person* with PWS
- Seek legal responsibility if necessary
- Written professional support
- Encourage support *not* control

# I Want the Same

The “same” includes many more things than just food.

People with PWS want

- To travel independently
- To have their own money
- To go out
- To eat the food, they see advertised
- To get married
- To have babies

➡ just like other youngsters or adults





# I Want the Same

## ISSUES



Noticing  
differences to  
peers and siblings



Desiring more  
independence



Why ?

- Care and assistance
- Troubles and conflicts
- Problems to live together, partnership

# I Want the Same



Parents and carers may think:

- Who are we to determine what is an “appropriate” achievement for another person?
- Remembering that people with PWS have limitations reinforces the need for boundaries in everything they do to protect them from serious health problems, mental illness, exploitation...

We will likely think that our loved ones with PWS do not have the same choice in life as most other people.  
This can be a source of grief and despair.

# I Want the Same

## STRATEGIES

- Knowledge about Prader-Willi-Syndrome
- Listen and empathise
- Provide choice – appropriate / limited
- Give responsibilities
- Encourage positive thinking to consider what they have rather what they are missing out on
- Maintain a busy schedule – Plan & prepare - routine
- Have boundaries (around internet use, money...)
- Provide the same for all where possible – BUT: confirm the choice for yourself
- Maintain consistency





# I Want the Same



## Conclusion:

- People with PWS are very ingenious / inventive to get over their limitations... BUT
- they also can arrange and accept the boundaries when they experience that they are accepted and understood – boundaries are necessary to maintain a healthy and safe life.

Don't forget: our human life moves between trial and error – no risk / no success



# Strength in Boundaries

## ISSUES

- People with PWS need guidelines or boundaries **to feel safe** and to respond to what is going on around them.
- Boundaries teach the person with PWS what is **desired by you and the society.**

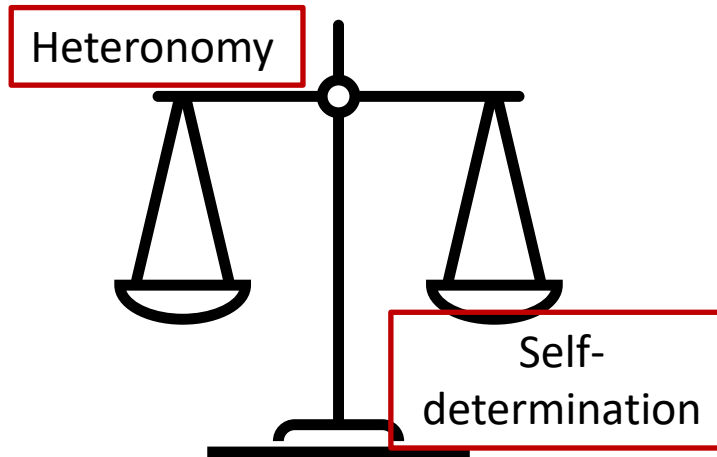


# Strength in Boundaries

Why?

## Security

- Good health
- less anxiety and less stress
- positive behavior
- stability



Integration in the society  
Ability to handle the social rules

**BUT**

Care based on overly strict and  
confusing structure causes  
challenging behavior



# Strength in Boundaries

## Strategies

People with PWS are **concrete thinkers** – they can accept rules, structures and boundaries when they understand the purpose.

### How?

- Integrate people with PWS in the determination of boundaries
- Use fewer words – less is more
- Too much choice is confusing
- Form of contract – use visual guides
- Power of consistency
- Consequences???



# Law Enforcement Matters



## ISSUES

Stealing food or money

Verbal or physical outbursts

Personal or property damage

Confabulation

Excessive contact with emergency services



## STRATEGIES

- Calm, confident communication
- Fewer, simple words in a gentle voice
- Avoid accusations, threats, false promises
- Interview with a trusted, PWS – knowledgeable adult
- Avoid offering food
- Avoid physical restraint
- Explain with visuals if possible
- Confirm their understanding of explanations or instructions
- Section 32



# Managing a Meltdown

## ISSUES

Heightened emotions  
Lack of control  
Refusal to move  
Screaming  
Hitting  
Self-harm  
Violence to people or objects

## STRATEGIES

- Validate
- Encourage coping strategies
- Distract, redirect or keep moving
- Keep calm, say less, quiet but confident voice
- Engage them in problem solving
- Maintain safety for all
- Give space and time
- *Review*
- *Practice coping strategies*



# Promoting Positive Behaviour Throughout Life

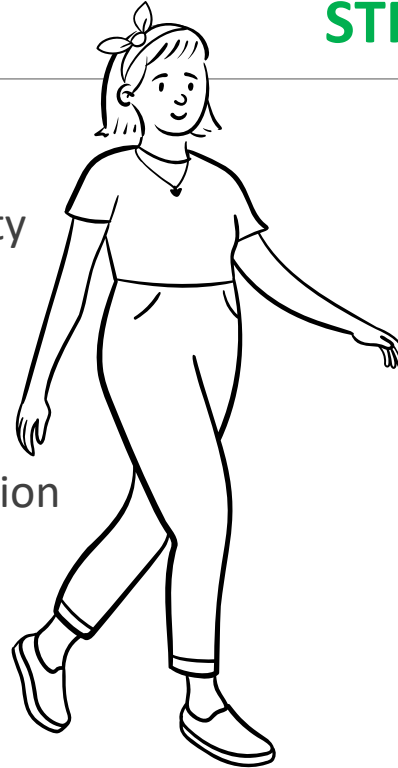
## ISSUES

- Heightened anxiety / awareness
- Emotional immaturity - Impulsivity
- Rigid thinking
- Egocentrism
- Poor comprehension and expression
- Inappropriate behaviour
- Hyperphagia
- Maintain respect



## STRATEGIES

- Preparation
- Clear Boundaries
- Visual guides
- Plan B
- Good example
- Limited choice
- Distraction / redirection
- Recapping
- Gentle prompting
- Calm reassurance
- Praise

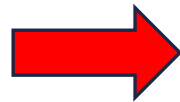


# Promoting Positive Behaviour Throughout Life



What does that mean to us as accompanying persons?? →

**shame, discomfort**



**Knowledge** and understanding people with PWS help us do deal with this discomfort:

**It is not our fault or our unsuccessful education!**

# Promoting Positive Behaviour

## ➤ Why do people with PWS engage in inappropriate behaviour?

“The behaviours associated with PWS, (..) are proposed to result from an interaction between biological predispositions due to impaired brain development and environmental factors.”

(IPWSO Mental Health Network Report, 2025)



# Promoting Positive Behaviour

## ISSUES - INAPPROPRIATE BEHAVIOUR

Why people with PWS engage in this inappropriate behaviour?

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- Emotional immaturity – Impulsivity - Poor comprehension and expression
- Rigid thinking
- Heightened anxiety - Egocentrism

### Limit to socialize

- Talking and jelling (eg. at movies)
- Loudly complaining in public
- Eating in inappropriate manner
- Staring at members of the public
- etc

# Promoting Positive Behaviour

## STRATEGIES

What should we do?



- **Remain calm!** The behaviour is not causing great danger!
- **Your knowledge and attitude** give security
- **Gentle prompts** can be useful without showing too much emotion.
- **Discuss and explain** the issue afterwards in non-stressful moments
- Create **sensitivity for other people**
- **Share your knowledge** with people involved in the PWS life

**PWS persons are able to adapt to a more positive behaviour !!!**

# Personal Care Too Hot Too Cold

## ISSUES

Hypothalamic thermodysregulation

Inability to feel hot or cold as others do

Unpredictable drops / rises in body temperature

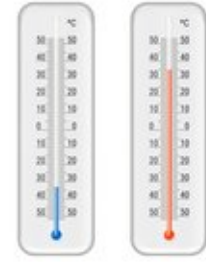
Over / under dressing for weather

Infections without raised temperature

Fevers without obvious infections

Poor sequential processing

## STRATEGIES



- teach appropriate clothing for different weather
- separate summer and winter clothing
- provide appropriate bedding for the season
- temperature controlled taps/showers
  - 37-38° Celsius (98 – 101° Fahrenheit) for children
  - 40-45° Celsius (104 – 113° Fahrenheit), for adults to avoid burning
- visual aids for Activities of Daily Living
- time showers
- notify medical professionals of thermodysregulation

# Skin Picking/ Bodily Picking

## ISSUES

Stress / anxiety

Boredom

High pain threshold

## STRATEGIES

- Investigate the cause of the stress
- Distract / keep hands busy
- Routine cutting of fingernails
- Moisturise skin / hands daily
- Calming sensory techniques
- Positive reinforcement for no picking
- Cover and treat sores as necessary
- Medications: topiramate / guanfacine



# Story Telling (Confabulation)

## ISSUES

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**Simple lie** to avoid trouble

**Manipulation** or wishful thinking

**Confabulation** - distorted memory

belief in collected of information

delusional thinking

## STRATEGIES

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- Do not ask “did you?”
- Openly “check with others”
- Listen to the whole story
- Remain calm
- Redirect with enhancement
- Use social stories
- Check use of multimedia
- Look for emotional stress
- Ask for explanations without directional language
- Investigate if suspicious
- Lena’s story

# The Importance of Planned Purposeful Days

## ISSUES

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Food focus

Anxiety / anxiousness

Post school transition

Suboptimal day programmes

Under utilised capabilities

Boredom

Behaviour smothers abilities

## STRATEGIES

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- Redirected concentration
- Planned days give direction
- New routine / schedule
- Responsibilities
- Improved self-esteem through achievements
- Employed like others
- Improved behaviour
- Needs-appropriate environment / staff education in PWS
- Encouragement awards
- Good sleep
- David's story

# Planned Purposeful Days

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A productive  
work day

*By Kade Gordon*

<https://www.youtube.com/watch?v=HkOfvflZHMU>

# When Rituals Become a Problem

## ISSUES

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Repetitive behaviours

Excessive use of commodities

Desiring sameness

Collecting

Hoarding

Attachment to people

## STRATEGIES

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- Plan for change – suggest an “adventure”
- Agreements around boundaries / limits
- Compliment on maturity in trialling change
- Start with small changes
- Use visuals of routine and time-limits



# Life Plan & Preparing for When Parents are Gone

## ISSUES

Individual

Desire for consistency

Absence of parents – for any reason

*Other* support people

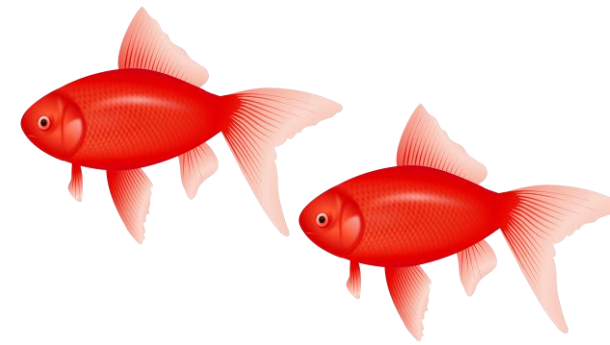
Impending long term separation

## STRATEGIES

- About “me”
  - my emotions
  - communicating with me
  - my family & home
  - my interests & possessions
  - health history
  - food interests
  - lifestyle (education/post school
  - personal care
  - financial information
  - people who help me
  - religion
  - final thoughts
- What I need
- Practice a change in routine
- Time with others, with & without parents present

**\*Life Plan** – permission from & thanks to,  
Kate Beaver USA

# Motivation



Red	RESPECT	■ For the person and PWS
C	CHALLENGE	■ Competitiveness and sense of achievement
A	ACQUIRED AGREEMENT	■ Sense of “self-choice”
R	RESPONSIBILITY	■ Trusting their ability improves self-esteem
R	REWARDS	■ Small / tangible / realistic / repeatable as a motivator
P	PRAISE	■ Encourages positive repetition, improves self esteem and mood
S	SECURITY	■ Reduces anxiety / improves capability

# Other FAMCARE Articles

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- EXERCISE
- HEALTH CHECKLIST
- HEALTHY ADULT LIFE – healthy lifestyle
- SUPPORT THROUGH COVID19 – *now obsolete*

# Where to from here for Famcare

United in HOPE  
2025 PWS CONFERENCE



New members  
New Family Forum presentations  
Global Family Mission

