



Building Research Capacity for Nursing &
Allied Health Professionals and Pharmacists
Cynyddu Gwalth Ymchwil ar gyfer Nyrsio a
Gweithwyr Proffesiynol Cysylliedig a Fferylwyr

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Today's Session



- My interest in Type 1 Diabetes and Disordered Eating
- Research project
- Call for help
- Plans for the future
- What's happening across Wales and beyond



About me

- Paediatric Diabetes Dietitian at Cardiff and Vale UHB
- Background : Paeds/WG obesity project/media work
- Surprised at eating distress
- Wondered if ‘we’ are part of the problem



What is a healthy relationship with food



What on earth is T1DE?

- Incidence
40% DEB/ 10% ED^{1,2,3}
- Diabulimia
- BMI not a good indicator



Box 1: Proposed diagnostic criteria for T1DE

People with type 1 diabetes who present with all three criteria:

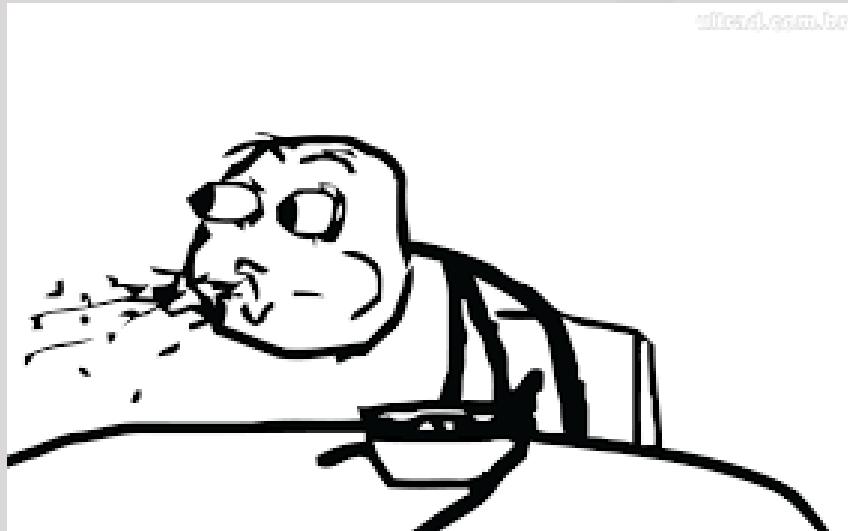
1. Intense fear of gaining weight, or body image concerns, or fear of insulin promoting weight gain.
2. Recurrent inappropriate direct or indirect* restriction of insulin (and/or other compensatory behaviour**) to prevent weight gain.
3. Presenting with a degree of insulin restriction, eating or compensatory behaviours that cause at least one of the following:
 - harm to health
 - clinically significant diabetes distress
 - impairment on daily functioning.

* Indirect restriction of insulin refers to reduced insulin need/use due to significant carbohydrate restriction.

** Dietary restriction, self-induced vomiting, laxative use, excessive exercise, over-use of thyroid hormones, over-use of diabetes medication believed to avoid weight gain or promote weight loss.



“It’s not like anybody has died of this”



“Your wasting your time
looking at eating
disorders and diabetes...
the real problem is
obesity not eating
disorders



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- Female insulin restrictors displayed high levels of eating disorder symptoms and the average age of death for frequent insulin restrictors was 45 years of age (Goebbel-Fabbri et al., 2008)

‘I became an expert in
controlling the
uncontrollable....’

RELAPSE

As the ferns glitter and stiffen, you'll pray for me
cleaved to the radiator, turning a book with my feet,

my fingers shoved like razor clams
behind coat-sleeves.

You'll pray for my bones dragging themselves to the bathroom,
my hand tugging the light, searching the pristine step

for my value in pounds. The dial
flickers. I lift my toes.

Every morning, I harvest myself: carry the web
of my tendons, gently pluck out the heart.

It flops miserably in my palm. Time now to weigh
the ounce of my life, blow

into dust and bone.

@natalieholborow



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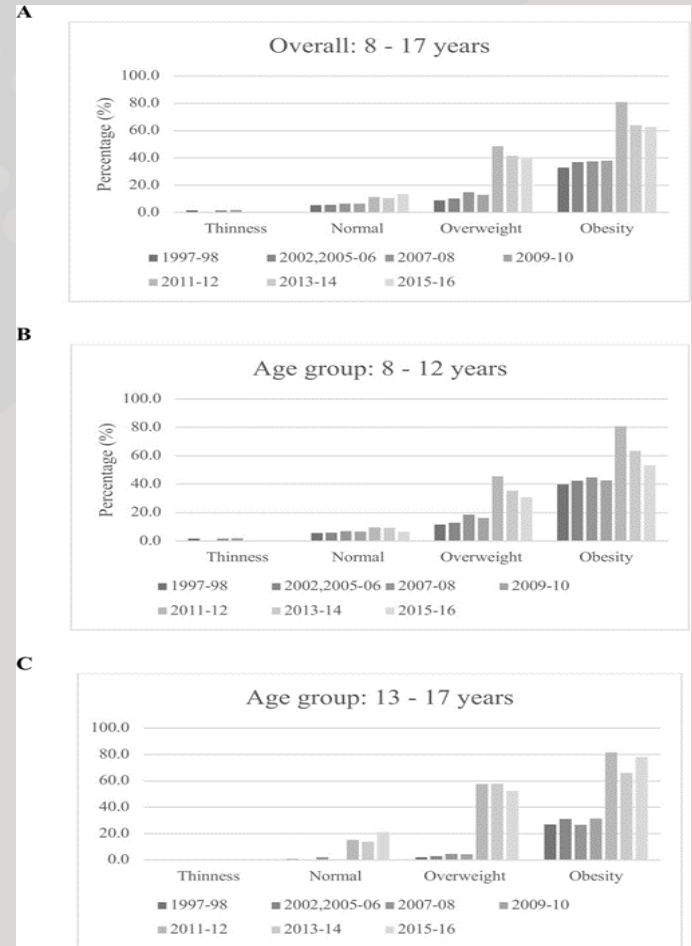


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Weight loss attempts in Childhood

- Weight loss attempts in childhood are rising at a greater rate than obesity rates are rising (Ahmad et al, 2022).
- Weight loss attempts are growing in healthy weight children
- Lower sociodemographic groups, females, ethnic minorities
- Glorifies thin-ness demonises obesity





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Research Aim

- This research aims to build on current understanding of Type 1 Diabetes (T1D) and disordered eating to improve services for children and young people (CYP) with diabetes in Wales



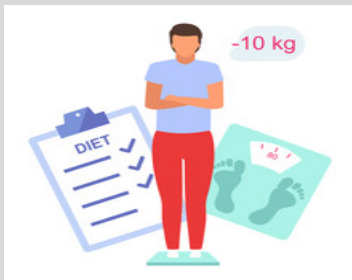
What do we know about the risks?



Psychological burden



Family life



Weight and shape concerns



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BOX 7 Risk factors and indicators of disordered eating behaviors in people with diabetes

Risk factors	Warning signs suspicion for early detection	Confirmation screening tools
<ul style="list-style-type: none"> • 7–18 years • Female • Detailed meal planning, precision in food proportion • Overweight, obesity • Body dissatisfaction • Anxious, poor quality of life • Poor attention in family to healthy eating, maternal overweight or binge-eating disorders in mothers 	<ul style="list-style-type: none"> • Suboptimal glycemic management • Recurrence of hypoglycemic events • Systematic calculations of caloric values and weighing of foods • Frequently missed medical check-ups • Refusal to be weighed • Concern for appearance • Tendency toward vegetarianism 	<ul style="list-style-type: none"> • Revised Diabetes Eating Problem Survey (DEPS-R) • Modified SCOFF (mSCOFF) test • Single question “Have you ever been overweight?”



Project plan

Phase 1: What can we learn from the lived experiences of people with Type 1 Diabetes to develop eating disorder prevention strategies in paediatric diabetes care

- Recruit adults with lived experience T1D and any form of disordered eating
- Semi-structured interviews
- Thematic analysis and service review to inform phase 2

Phase 2/3: To build on existing research and patient insights to develop an appropriate intervention to support early prevention of T1DE within structured education and healthcare interaction for CYP.

1. How can the patient voice support the development of an intervention for the prevention of eating disorders within paediatric diabetes care?
2. When should an eating disorder intervention take place within paediatric diabetes care?
 - What will this intervention look like
 - Co- develop an intervention/service change embedded in our structured education programmes
 - Develop and conduct a feasibility study of early intervention for CYP to inform a future RCT



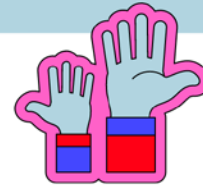
Where am I?



DO YOU LIVE WITH TYPE 1 DIABETES AND HAVE YOU PREVIOUSLY EXPERIENCED DISORDERED EATING?

We want your help understanding why people develop Type 1 Diabetes and Disordered Eating (T1DE)

Would you like to help improve services for children and young people with diabetes?



Do you want your story to inform strategies to prevent eating disorders in diabetes?



Eligibility criteria: Participants must*

- Live with Type 1 Diabetes
- Have received care from a paediatric diabetes team in the United Kingdom
- Identify as having experienced disordered eating

* Participants will not be eligible if this research is deemed harmful to their current wellbeing



Scan the QR to
or follow the
link attached to
register your
interest



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Follow us on social media and help us
prevent eating disorders in Type 1
Diabetes

 @PreventT1DE
 @PreventT1DE

Data collection

- Recruiting via social media @TT1DE
 - T1D, diagnosed in paediatrics, not active ED diagnosis or meet proposed criteria
- 2/20 interviews complete
- 22 people registered interest, only 6 eligible, 3 didn't leave contact details
- 8/22 do not identify as heterosexual (i.e. gay/lesbian/homosexual or bisexual)
- 10/22 identify as neurodiverse (either diagnosed or seeking diagnosis)



What makes sense

- Shame around eating
- Feeling let down by parents
- Being weighed in clinic
- Healthcare professional weigh stigma
- Healthcare professional thin preferences

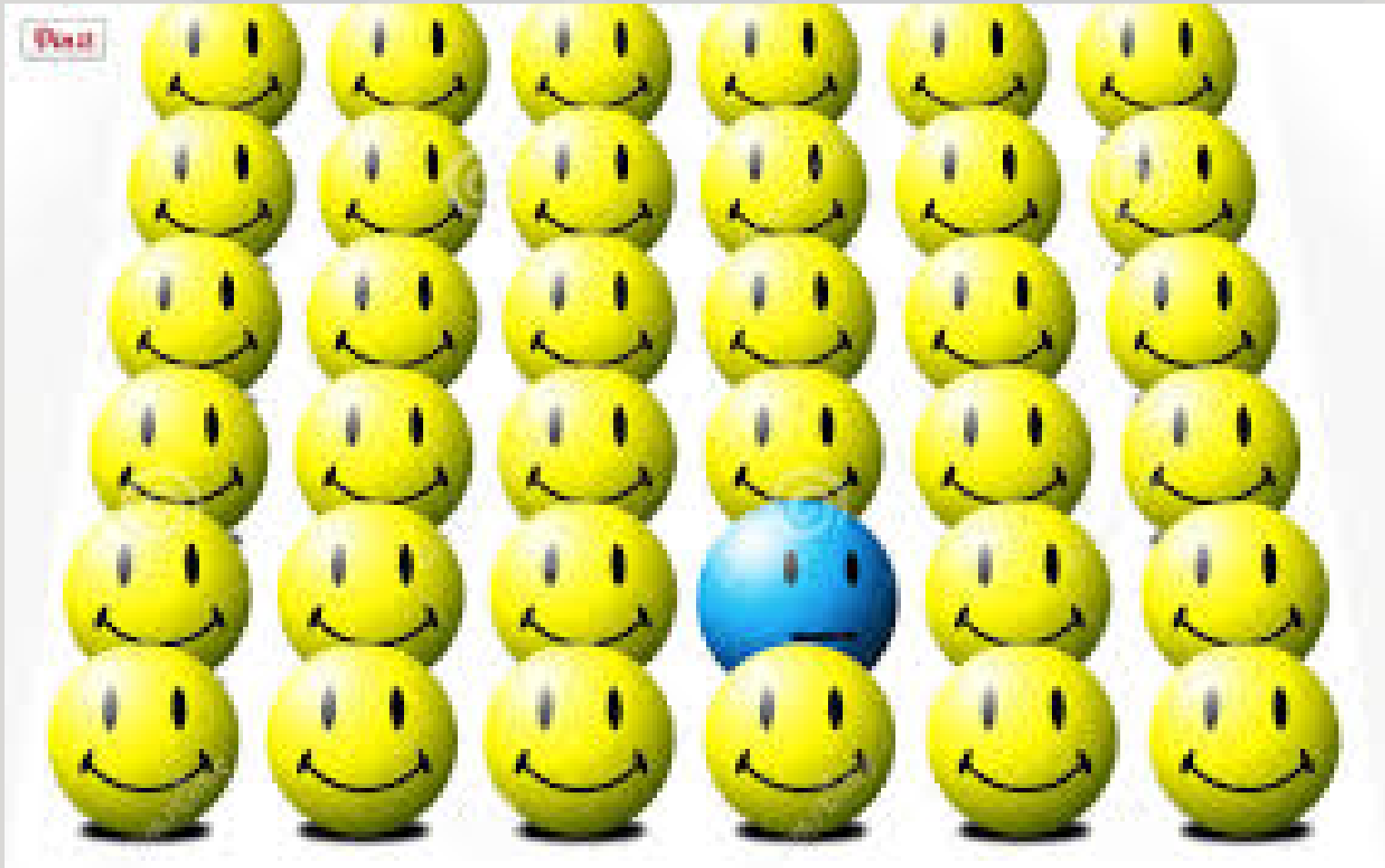


What is surprising me

- Not the education, but the families reaction to the education
- PTSD
- Attachment issues
- ‘Eating disorder behaviour’ completely different, but the themes and level of distress is similar (e.g. restriction vs binging)
- DKA admissions secondary to binge eating



Working with Psychology



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Prevention is my passion

- But.....



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Ones to watch

- Sarah Alicea – Diabetes Dietitian and T1DE practitioner at Barts SARAH.ALICEA@nhs.net
- @T1DERecovery – Turning the T1DE from Bangor University
- Priority Study
- Many more in the #DeDOC including....
- Rachael Humphreys – All Wales T1DE Lead



AWDIG

Type 1 Diabetes and Eating Disorders (T1DE)

Rachael Humphreys

Paediatric Diabetes Specialist Nurse, CAV
All Wales Lead Type 1 Diabetes and Eating Disorders, AWDIG



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THE CONVERSATION IS JUST STARTING

- Awareness of T1DE is growing
- Parliamentary Inquiry
- MEED Annexe 3 – Type 1 Diabetes and Eating Disorders (replacing MARSIPAN and Junior MARSIPAN) – published May 2022
- Wessex ComPASSION Pilot
 - National pilot integrating diabetes and mental health pathway
 - Assessment, referral and treatment of T1DE
 - Five further sites funded across England to deliver this integrated service in 2023
 - Publication of A Guide To Risk Assessment for Type 1 Diabetes and Disordered Eating (T1DE) in 2021
- PRIORITY trial
 - Seeks to prevent T1DE through a brief, low intensity, psychological intervention
 - Multi-component psycho-educational programme delivered to parents



PROGRESS SO FAR IN WALES

- National Steering Group Clinical Forum across all health boards
- Establishment of Strategy groups within each health board (aim is to have representation from all areas – diabetes, dietetics, psychology, mental health/eating disorder teams)
- Establishment of Consultation groups within each health board (members of the team discuss patients of concern with local ED/MH team and gain advice)
- Online consultation session with the help of BEAT to gain insight into the lived experience of Type 1 Diabetes and the impact this may have on their relationship with food and body image
- Breathe Creative Project with adults who have a lived experience of T1DE and animation ‘Swimming with the T1DE’ which was shown at the Parliamentary Enquiry into Type 1 Diabetes and Eating Disorders
- Linking in with services, healthcare professionals, JDRF/Diabetes UK Cymru/BEAT



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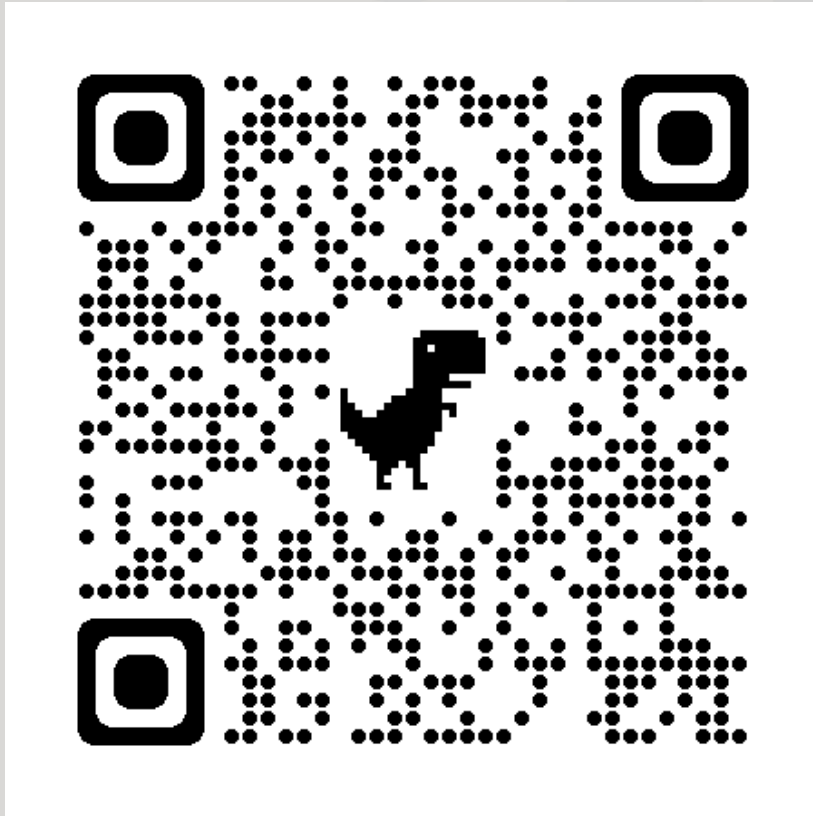
WHAT'S NEXT?

Courageous Conversations

- Language documents on how we can have sensitive conversations with patients around body image and weight
- Early Intervention Care Pathway to be explored across health boards
 - Ask – questions and red flags (e.g. are you happy with your life at the moment? Red flag could be a reluctance/refusal to be weighed)
 - Screen – SEEDS and DEPs-R
 - Support – take to Consultation group, consider referral, MDT approach
 - Referral – Discuss in Consultation group, consider referral, MDT approach.
 - Immediate risk results in referral
- Is training required for this or can this be done ‘in house’?
- Follow-on project with Breathe Creative to further explore the individual experience of T1DE and a sharing event to exhibit the work
- Diabetes UK Cymru sponsored event



Call to Action



- Challenge weight stigma
- Consider screening
- Any advice or support in recruitment!



References

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Thank you

This is
my
thank you
dance!



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