Paramedic Community of Practice – Series 2

Addressing management of neurodiverse populations receiving a palliative approach to care

Project ECHO
Palliative Care - Canada
BY Pallium Canada

Facilitator: Diana Vincze, Pallium Canada
Presenter: Dr. Jitin Sondhi
Date: May 14th, 2024

Territorial Honouring

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness.

Stay connected: www.echopalliative.com

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Project ECHO Palliative Care - Canada BY Pallium Canada

LEAP Paramedic

Learn the essentials for providing a palliative care approach

- Ideal for Paramedics and Emergency Medical Service professionals

- **Key features:**
  - Created and reviewed by Canada's leading palliative care experts
  - Taught by local paramedic experts and experienced palliative care practitioners
  - Nationally recognized certificate
  - Evidence-based and case-based

Learn more about the course and topics covered by visiting

https://www.pallium.ca/course/leap-paramedic/

Introductions

Facilitator:
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Palliative Care ECHO Project Manager

Presenter:
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Regional Clinical Co-Lead, Palliative Care, OH West
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Panelists:

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Provincial Palliative Care Practice Leader, NS
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Kristina Anton, ACP
Paramedic Specialist, BC Emergency Health Services

Karen O'Brien
Frontline Paramedic since 1999, with a side of community paramedicine.
SWORBHP Associate Instructor
Pallium Facilitator

Stuart Woolley
Paramedic since 2003 in UK & Canada, current Paramedic Practice Leader in BCEHS leading Palliative Care, Low Acuity Patient management & Paramedic Specialist support.

Welcome and Reminders

- Please introduce yourself in the chat!
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the Q&A function for questions, they will be addressed during the discussion/question period.
- Remember not to disclose any Personal Health Information (PHI) during the session.
- This session is being recorded and will be emailed to registrants within the next week.

Overview of Topics

Session #	Session title	Date/ Time
Session 1	Self-Care	November 14, 2023 from 12–1:00 p.m. ET
Session 2	Serious illness conversations	January 16, 2024 from 12–1:00 p.m. ET
Session 3	Alternate destination in paramedicine; redirection to institutions other than a hospital	March 12, 2024 from 12–1:00 p.m. ET
Session 4	Addressing management of neurodiverse populations receiving a palliative approach to care	May 14, 2024 from 12–1:00 p.m. ET
Session 5	Pain and Symptom Management	July 22, 2024 from 12–1 p.m. ET

Session Learning Objectives

- Understanding terminology and target population
  - Neurodiverse vs People with Intellectual and Developmental Disability (PWIDD)
- Current landscape and health care challenges faced for PWIDD
- Palliative Care and PWIDD

Special Thanks to

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Understanding Terminology

- Neurodiversity describes the idea that people experience and interact with the world around them in many different ways; there is no one "right" way of thinking, learning, and behaving, and differences are not viewed as deficits. (By Dr. Nicole Baumer, MD, Med, From Harvard Medical)
- Term was created by Australian Sociologist Judy Singer as part of a social justice movement to promote inclusivity and equity.

- Term used for research and policy exploration:
  - People with Intellectual and Developmental Disabilities (PWIDD)

Intellectual and Developmental Disability (IDD)

- An umbrella term for different disabilities that involve the person having "prescribed significant limitations in cognitive and adaptive functioning and those limitations
  - Originated before the person reached 18 years of age
  - Are likely to be life-long in nature; and
  - Affect areas of major life activity

- **Cognitive** functioning refers to
  - “a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences
- **Adaptive** functioning speaks to
  - “a person’s capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills in everyday life

Intellectual and Developmental Disability (IDD)

- Umbrella term for disabilities involving significant limitations in cognitive and adaptive functioning
  - Many are life-limiting and result in significant health issues

Genetic Etiologies	Global Etiologies	Pre/Post Natal Injury Etiologies
Deletion Syndrome(s) e.g., Fragile X, Prader-Willi, Angelman, Rhett Syndrome, Smith Magenis Syndrome Williams Syndrome Down's Syndrome	Global Developmental Delay (unknown etiology) Autism Spectrum Disorder	Fetal Alcohol Syndrome (FAS) Cerebral Palsy (if meets the DSO Criteria) Maternal Rubella Neurologic sequela of early childhood meningitis

(Developmental Disabilities Primary Care Initiative, 2011; Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008)

Palliative Care for People with Intellectual and Developmental Disabilities (PWIDD)

- PWIDD, many with complex needs, lack equitable access to palliative care, including providers with confidence and competency in IDD palliative care
- Existing palliative care frameworks and tools are not directly transferable to IDD
- Standard palliative care approach for PWIDD and adequate resourcing is lacking

Premature Aging and Premature Death

Premature Biological Aging

- More rapid physiological/biological aging
  - est. 30 years older than Chronological age

Neuro-Atypical Aging

- Dementia presents earlier (30- 40 years old)
- High incidence Alzheimer's which progresses more rapidly

Premature Death

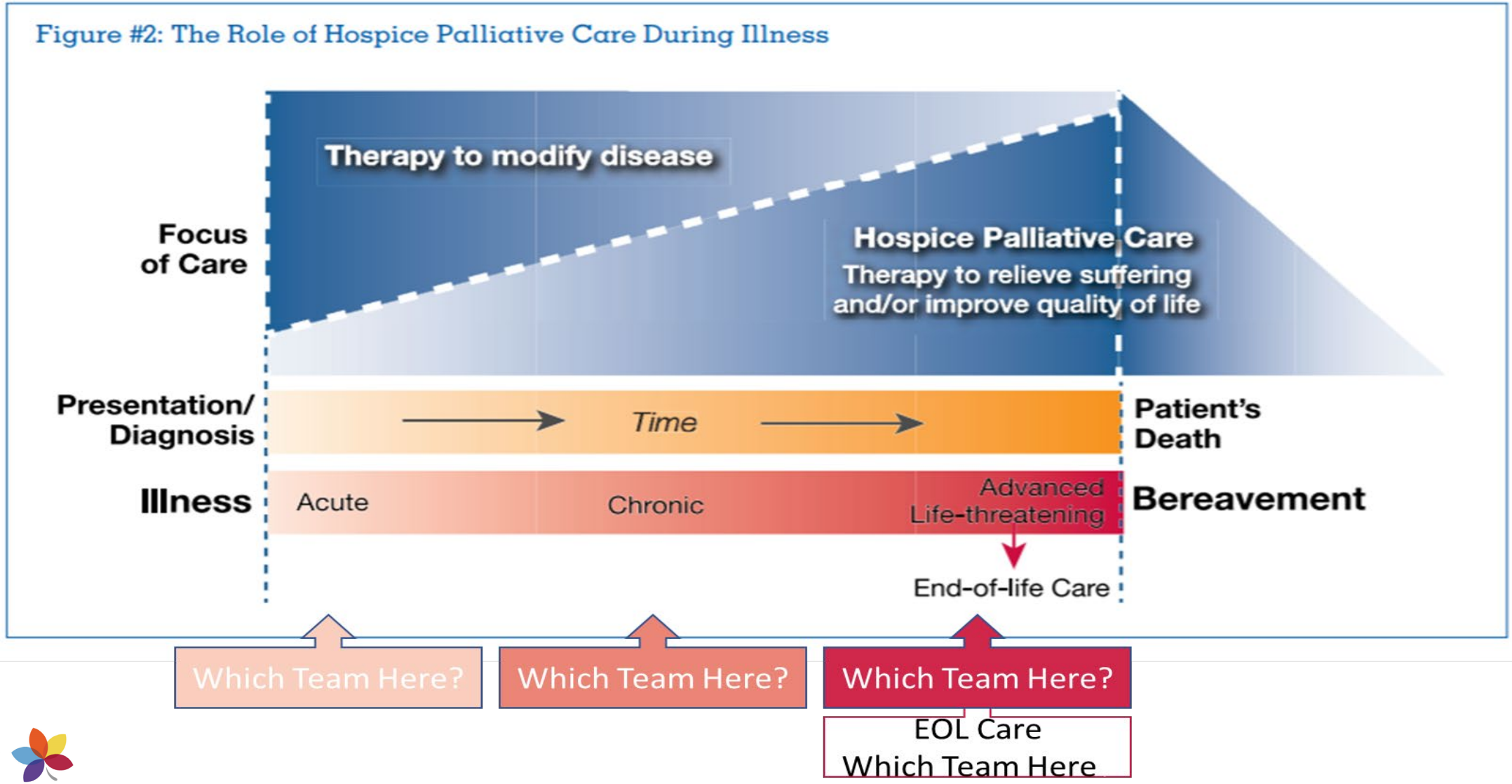
- x4 more likely to die prematurely
- Median age at death = 55 – 64 years
  - 30 - 40 years of age if severe/profound level of IDD

Leading Causes of Death

- Cardio/pulmonary (36%); Cancer (29%); Sudden Unexpected Death in Epilepsy (30%); Nervous system disorders (Congenital; Chromosomal) (7%); Distinct (lifelong) frailty (4%)

(Heslop et al., 2014; Stankiewicz et al., 2018; Strydom et al., 2010)

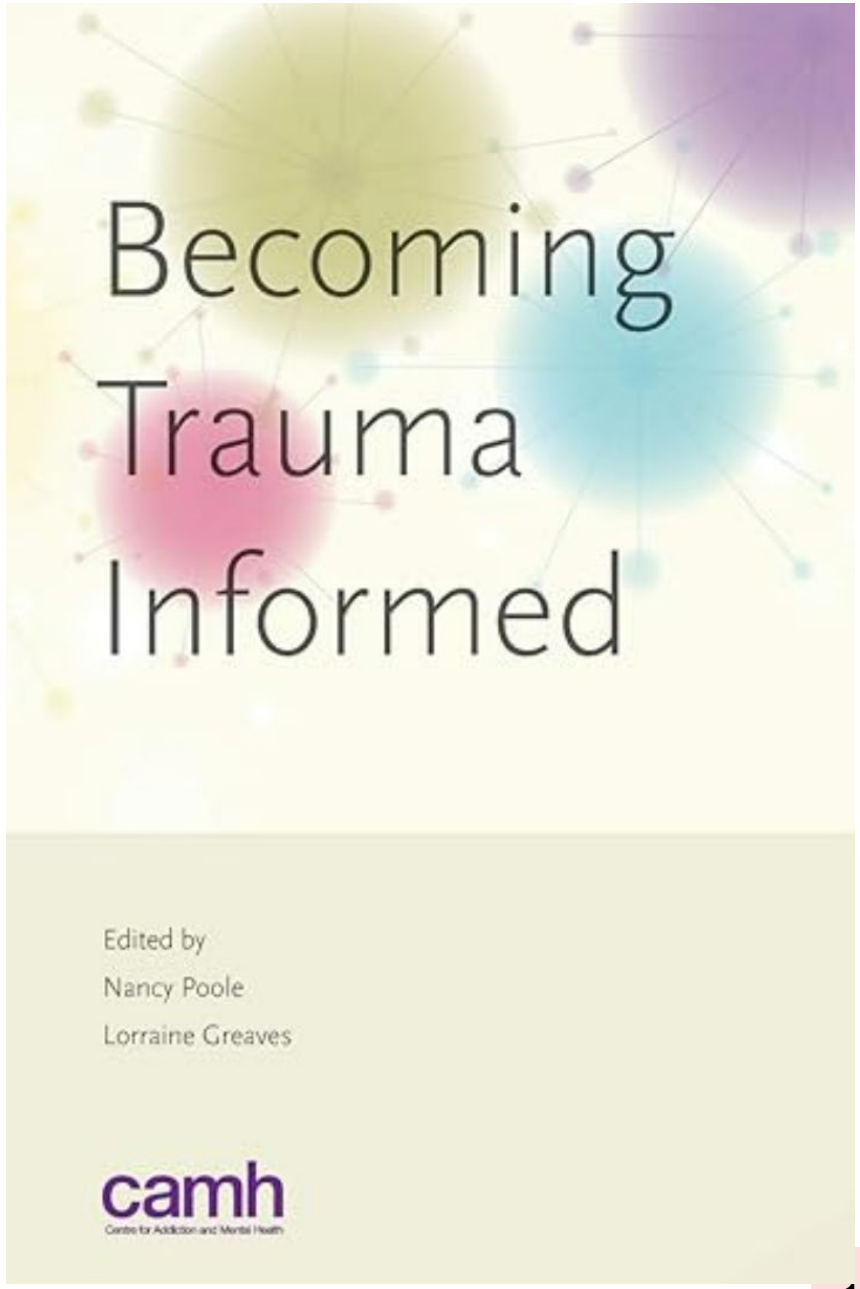
Not Only an Illness Journey but A Life Story for PWIDD



Medical Traumatization

- Far more likely to be victimized than the general population, yet have fewer resources to deal with these experiences
- 70% of PWIDD have 1 trauma experience, multiple is the norm – PTSD is common
- Trauma Informed Care Approaches are a MUST

(Lunsky & Palucka, CAMH, 2012)



Medically Complex and Health Resource Utilization

People with developmental disabilities fare worse in the health system across multiple indicators

IC/ES

Report from ICES finds that Ontario adults with developmental disabilities experience worse health outcomes, regardless of age, sex, neighbourhood income or type of developmental disability. For most indicators, these outcomes are more likely with age.

The researchers looked at health records for nearly 65,000 Ontarian adults under the age of 65 with developmental disabilities such as Down syndrome or autism. They looked at the records over a six year period (2010-2016) and compared them to Ontarians who don't have these disabilities.

"I would like doctors to have a little more time for people with disabilities, and be more understanding. We're a little slower than other people are. We need more time to talk to them."

— Michael, self-advocate

HIGHER RATES OF POOR HEALTH OUTCOMES FOR ADULTS WITH DEVELOPMENTAL DISABILITIES COMPARED TO ADULTS WITH NO DEVELOPMENTAL DISABILITIES

ONTARIO (2010 - 2016)

30-DAY REPEAT ED VISITS	30-DAY REPEAT HOSPITALIZATIONS	ALTERNATE LEVEL OF CARE	LONG-TERM CARE	PREMATURE MORTALITY
Likelihood of having at least one return visit to an ED within 30 days of an earlier visit or hospitalization.	Likelihood of having a repeat hospitalization within 30 days of a previous discharge.	Likelihood of having to remain in hospital despite being recovered enough for discharge.	Likelihood of living in a long-term care facility.	Likelihood of dying before the age of 75 years.
Nearly 2X higher	More than 3X higher	6.5X higher	17.5X higher	Nearly 4X higher
34.5% vs. 19.6% (DD / no DD)	7.4% vs. 2.3% (DD / no DD)	4.6% vs. 0.7% (DD / no DD)	3.5% vs. 0.2% (DD / no DD)	6.1% vs. 1.6% (DD / no DD)

Lin E et al. *Addressing Gaps in the Health Care Services Used by Adults with Developmental Disabilities in Ontario.* ICES; 2019.

ICES *Data. Discovery. Better Health.* ices.on.ca

HCARDD Health Care Access Research and Developmental Disabilities

UNIVERSITY OF ONTARIO INSTITUTE OF TECHNOLOGY

camh mental health is health

https://www.ices.on.ca/~/media/Images/News_releases/2019/HCARDDReport2019.ashx?la=en-CA

PWIDD and Palliative Care

- Existing tools and resources available have not been tested or validated for PWIDD
  - Not accommodating for life-long frailty
  - Do not take into consideration decline comparison to IDD specific baselines
  - Existing scales can be too abstract
  - Functional measures used for scales do not take into consideration baseline functional changes

- This makes it challenging to use existing tools for:
  - Early Identification
  - Pain and Symptom Screening

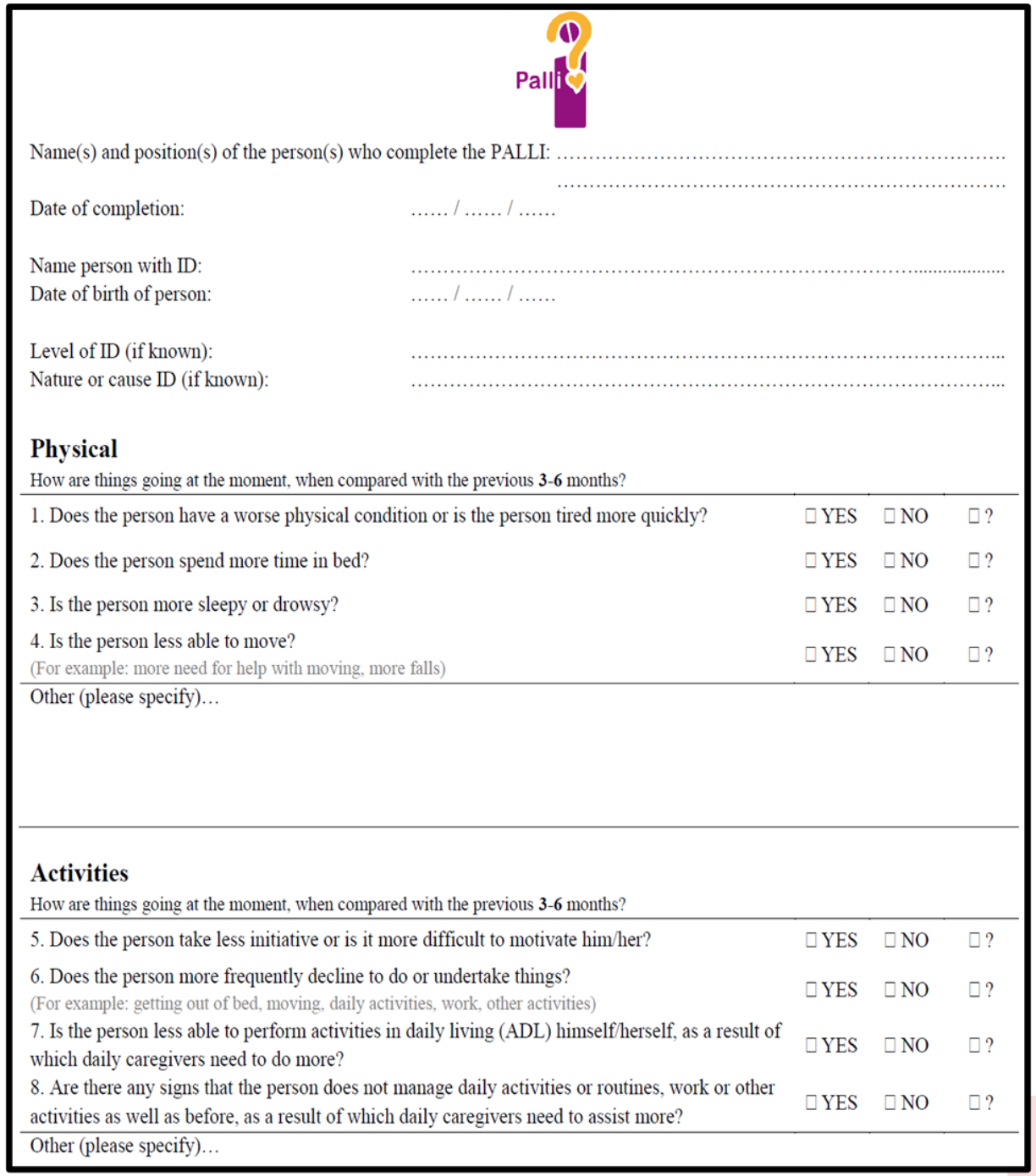
Earlier ID in IDD

PALLI is the first tool to address early identification of people living with IDD

Identifies warning signs of decline from baseline

Triggers further assessment to assign meaning of change i.e. an exacerbation event or transitioning to end-of-life care needs

Informs translation to PPS score for program services admission



Palli

Name(s) and position(s) of the person(s) who complete the PALLI: .....

.....

Date of completion: ..... / ..... / .....

Name person with ID: .....

Date of birth of person: ..... / ..... / .....

Level of ID (if known): .....

Nature or cause ID (if known): .....

Physical

How are things going at the moment, when compared with the previous **3-6** months?

1. Does the person have a worse physical condition or is the person tired more quickly?	☐ YES	☐ NO	☐ ?
2. Does the person spend more time in bed?	☐ YES	☐ NO	☐ ?
3. Is the person more sleepy or drowsy?	☐ YES	☐ NO	☐ ?
4. Is the person less able to move? (For example: more need for help with moving, more falls)	☐ YES	☐ NO	☐ ?

Other (please specify)…

Activities

How are things going at the moment, when compared with the previous **3-6** months?

5. Does the person take less initiative or is it more difficult to motivate him/her?	☐ YES	☐ NO	☐ ?
6. Does the person more frequently decline to do or undertake things? (For example: getting out of bed, moving, daily activities, work, other activities)	☐ YES	☐ NO	☐ ?
7. Is the person less able to perform activities in daily living (ADL) himself/herself, as a result of which daily caregivers need to do more?	☐ YES	☐ NO	☐ ?
8. Are there any signs that the person does not manage daily activities or routines, work or other activities as well as before, as a result of which daily caregivers need to assist more?	☐ YES	☐ NO	☐ ?

Other (please specify)…

Available from: Cis Vrijmoeth, Intellectual Disabilities and Health, Department of Primary and Community Health Care, Radboudumc Nijmegen, Nijmegen, The Netherlands.
Email: cis.vrijmoeth@sheerenloo.nl

SPICT-4ALL

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

(eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

Project ECHO Palliative Care - Canada BY Pallium Canada

Pain and Symptom Screening

Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness (Tiredness = lack of energy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness (Drowsiness = feeling sleepy)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7				Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4						10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1						7	8	9	10	Worst Possible Shortness of Breath
No Depression (Depression)					4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety (Anxiety = feeling nervous)			1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing (Wellbeing = how you feel overall)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem (for example constipation)	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Too abstract

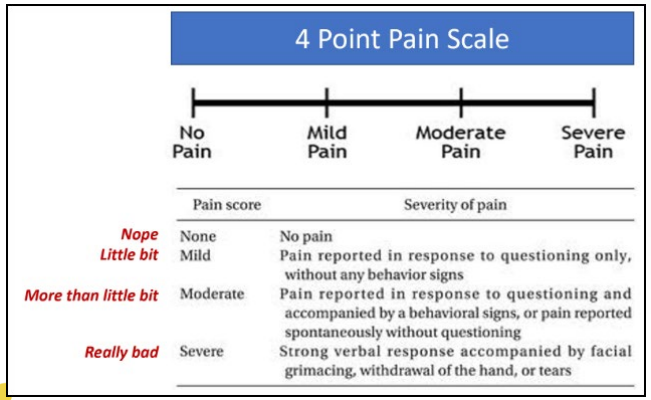
Patient's Name _____

Date _____ Time _____

Completed by (check one):
- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

BODY DIAGRAM ON REVERSE SIDE

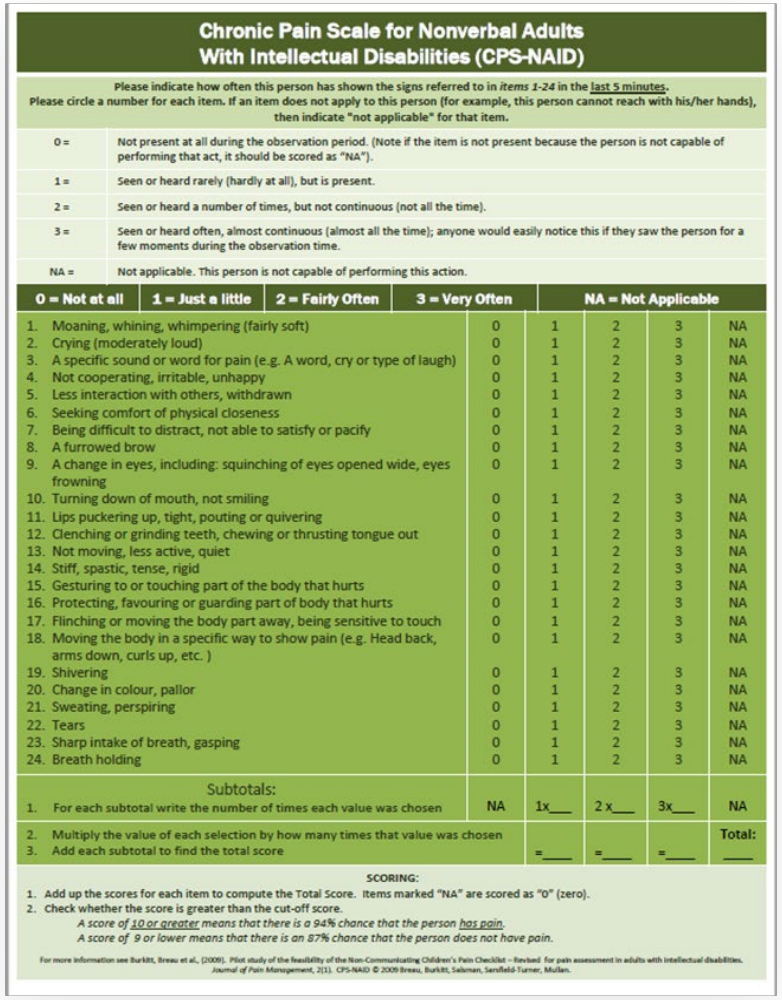
ESAS-r
Revised November 2010



4 Point Pain Scale

No Pain — Mild Pain — Moderate Pain — Severe Pain

	Pain score	Severity of pain
Nope	None	No pain
Little bit	Mild	Pain reported in response to questioning only, without any behavior signs
More than little bit	Moderate	Pain reported in response to questioning and accompanied by a behavioral signs, or pain reported spontaneously without questioning
Really bad	Severe	Strong verbal response accompanied by facial grimacing, withdrawal of the hand, or tears



Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in *items 1-24* in the last 5 minutes.
Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

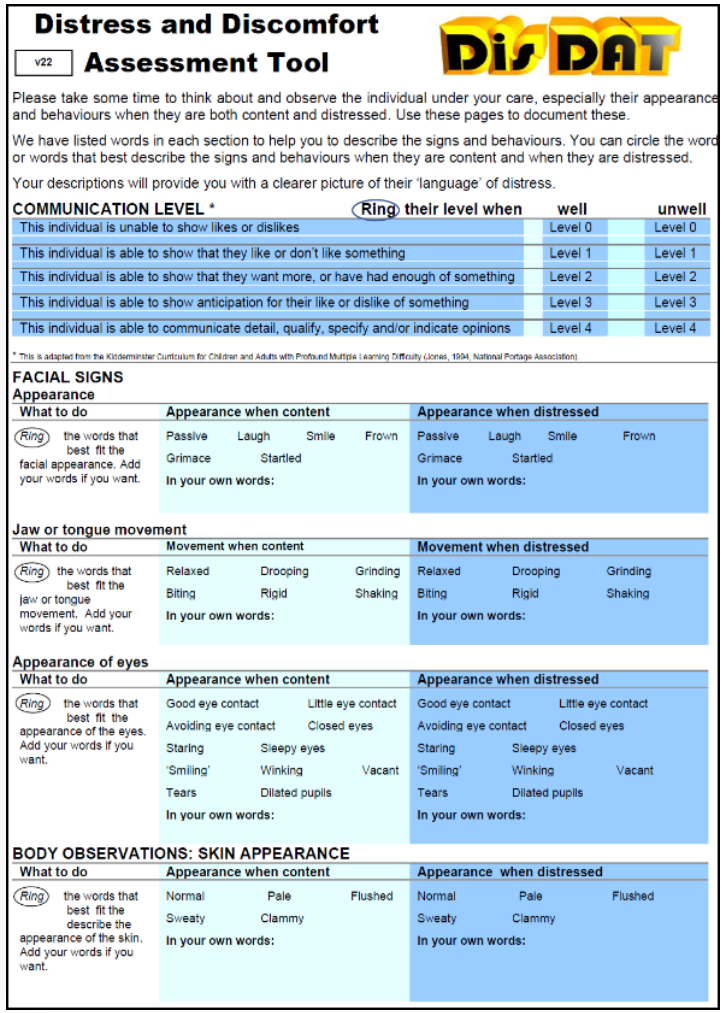
0 =	Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
1 =	Seen or heard rarely (hardly at all), but is present.
2 =	Seen or heard a number of times, but not continuous (not all the time).
3 =	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
NA =	Not applicable. This person is not capable of performing this action.

	0 = Not at all	1 = Just a little	2 = Fairly Often	3 = Very Often	NA = Not Applicable
1.	Moaning, whining, whimpering (fairly soft)	0	1	2	3	NA
2.	Crying (moderately loud)	0	1	2	3	NA
3.	A specific sound or word for pain (e.g. A word, cry or type of laugh)	0	1	2	3	NA
4.	Not cooperating, irritable, unhappy	0	1	2	3	NA
5.	Less interaction with others, withdrawn	0	1	2	3	NA
6.	Seeking comfort of physical closeness	0	1	2	3	NA
7.	Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
8.	A furrowed brow	0	1	2	3	NA
9.	A change in eyes, including: squinching of eyes opened wide, eyes frowning	0	1	2	3	NA
10.	Turning down of mouth, not smiling	0	1	2	3	NA
11.	Lips puckering up, tight, pouting or quivering	0	1	2	3	NA
12.	Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA
13.	Not moving, less active, quiet	0	1	2	3	NA
14.	Stiff, spastic, tense, rigid	0	1	2	3	NA
15.	Gesturing to or touching part of the body that hurts	0	1	2	3	NA
16.	Protecting, favouring or guarding part of body that hurts	0	1	2	3	NA
17.	Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
18.	Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)	0	1	2	3	NA
19.	Shivering	0	1	2	3	NA
20.	Change in colour, pallor	0	1	2	3	NA
21.	Sweating, perspiring	0	1	2	3	NA
22.	Tears	0	1	2	3	NA
23.	Sharp intake of breath, gasping	0	1	2	3	NA
24.	Breath holding	0	1	2	3	NA
	Subtotals:					
1.	For each subtotal write the number of times each value was chosen	NA	1x___	2 x___	3x___	NA
2.	Multiply the value of each selection by how many times that value was chosen					Total:
3.	Add each subtotal to find the total score		=___	=___	=___	___

SCORING:
1. Add up the scores for each item to compute the Total Score. Items marked "NA" are scored as "0" (zero).
2. Check whether the score is greater than the cut-off score.
   A score of 10 or greater means that there is a 94% chance that the person has pain.
   A score of 9 or lower means that there is an 87% chance that the person does not have pain.

For more information see Burkitt, Breau et al., (2009). Pilot study of the feasibility of the Non-Communicating Children's Pain Checklist – Revised for pain assessment in adults with intellectual disabilities. *Journal of Pain Management*, 2(1). CPS-NAID © 2009 Breau, Burkitt, Salsman, Sarsfield-Turner, Mullan.

https://ddprimarycare.surreyplace.ca/guidelines/general-health/pain-and-distress/



Distress and Discomfort Assessment Tool

v22 DisDAT

Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

COMMUNICATION LEVEL * (Ring their level when)	well	unwell
This individual is unable to show likes or dislikes	Level 0	Level 0
This individual is able to show that they like or don't like something	Level 1	Level 1
This individual is able to show that they want more, or have had enough of something	Level 2	Level 2
This individual is able to show anticipation for their like or dislike of something	Level 3	Level 3
This individual is able to communicate detail, qualify, specify and/or indicate opinions	Level 4	Level 4

* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association)

FACIAL SIGNS

Appearance

What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the facial appearance. Add your words if you want.	Passive Laugh Smile Frown Grimace Startled In your own words:	Passive Laugh Smile Frown Grimace Startled In your own words:

Jaw or tongue movement

What to do	Movement when content	Movement when distressed
(Ring) the words that best fit the jaw or tongue movement. Add your words if you want.	Relaxed Drooping Grinding Biting Rigid Shaking In your own words:	Relaxed Drooping Grinding Biting Rigid Shaking In your own words:

Appearance of eyes

What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the appearance of the eyes. Add your words if you want.	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils In your own words:	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils In your own words:

BODY OBSERVATIONS: SKIN APPEARANCE

What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the describe the appearance of the skin. Add your words if you want.	Normal Pale Flushed Sweaty Clammy In your own words:	Normal Pale Flushed Sweaty Clammy In your own words:

DISDAT – Distress and Discomfort Assessment Tool

Prevalence of Pain in Children with SNI

- In a study of children with CP by Svedberg et al, 2002, of the children who experienced pain, more than 90% had experienced recurrent pain for > 1 year, yet only half were receiving any treatment directed at pain.
  - Pain in some is chronic, occurring on a weekly to daily basis and persisting despite treatment of problems such as GERD and spasticity

- In a similar study (Breau et al, 2003), pain was noted to occur ***weekly in 44%*** of children with moderate to severe cognitive impairment and ***almost daily in 42%*** of children with severe to profound impairment.

Marked contrast to typically developing children, with only 12% identified in a large population-based survey to experience pain on a weekly basis.
(Perquin, 2000)

Slide borrowed with permission from Dr. Sara Glazer
MD FRCPC Pediatrics

The FLACC Pain Scale

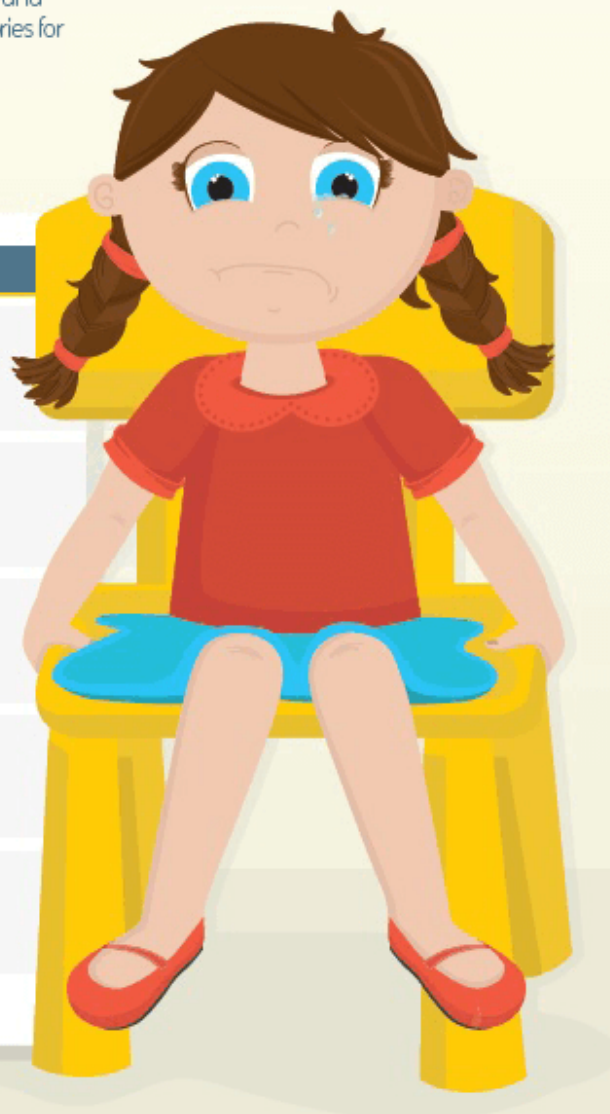
Sometimes it is difficult to assess pain in children who are non-verbal. The FLACC Pain Scale is a system that can help parents and professionals assess pain levels in children who have limited or no expressive communication. The diagram shows the categories for scoring. Zero, one or two points are given to each of the five categories: Face, Legs, Activity, Cry and Consolability.

Interpreting the Behaviour Score
Each category is scored on the 0-2 scale, which results in a total score of 0-10

0	relaxed and comfortable	4-6	moderate pain
1-3	mild discomfort	7-10	severe discomfort of pain or both

Categories ▼	Score Zero ▼	Score One ▼	Score Two ▼
Face F	No particular expression or smile	Ocasional grimace or frown, withdrawn, disinterested	Frequent to constant quivering chin, clenched jaw
Legs L	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity A	Lying quietly, normal position moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
Cry C	No crying (awake or asleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability C	Content, relaxed	Reassured by occasional touching, hugging or being talked to, distactable	Difficult to console or comfort

If a child is showing these behaviours, it doesn't necessarily mean that they are in pain, as some of the behaviours measured by the FLACC scale can happen for other reasons. However, parents are advised to follow up high scores with a professional.



CEREBRA
Working wonders for children with brain conditions

REFERENCE Merkel, S.I., Voepel-Lewis, T. Shayevitz, J.R., and Malviya, S. (1997). The FLACC: A behavioural scale for scoring postoperative pain in young children. *Pediatric Nursing, 23(3), 293-297.*

Non-communicating Children's Pain Checklist – Revised (NCCPC-R)

NAME:_____ UNIT/FILE #:_____ DATE:_____(dd/mm.yy)

OBSERVER:_____ START TIME:_____AM/PM STOP TIME:_____AM/PM

How often has this child shown these behaviours in the last 2 hours? Please circle a number for each item. If an item does not apply to this child (for example, this child does not eat solid food or cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = NOT AT ALL	1 = JUST A LITTLE	2 = FAIRLY OFTEN	3 = VERY OFTEN	NA = NOT APPLICABLE

I. Vocal						
1. Moaning, whining, whimpering (fairly soft)……..	0	1	2	3	NA
2. Crying (moderately loud)……..	0	1	2	3	NA
3. Screaming/yelling (very loud)……	0	1	2	3	NA
4. A specific sound or word for pain (e.g., a word, cry or type of laugh)……..	0	1	2	3	NA
II. Social					
5. Not cooperating, cranky, irritable, unhappy……..	0	1	2	3	NA
6. Less interaction with others, withdrawn……	0	1	2	3	NA
7. Seeking comfort or physical closeness ……..	0	1	2	3	NA
8. Being difficult to distract, not able to satisfy or pacify……	0	1	2	3	NA
III. Facial					
9. A furrowed brow……..	0	1	2	3	NA
10. A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning	0	1	2	3	NA
11. Turning down of mouth, not smiling……..	0	1	2	3	NA
12. Lips puckering up, tight, pouting, or quivering……	0	1	2	3	NA
13. Clenching or grinding teeth, chewing or thrusting tongue out ……..	0	1	2	3	NA
IV. Activity					
14. Not moving, less active, quiet…….. ……	0	1	2	3	NA
15. Jumping around, agitated, fidgety……..	0	1	2	3	NA
V. Body and Limbs					
16. Floppy ……	0	1	2	3	NA
17. Stiff, spastic, tense, rigid ……	0	1	2	3	NA
18. Gesturing to or touching part of the body that hurts ……	0	1	2	3	NA
19. Protecting, favoring or guarding part of the body that hurts ……	0	1	2	3	NA
20. Flinching or moving the body part away, being sensitive to touch……..	0	1	2	3	NA
21. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.) ……	0	1	2	3	NA
VI. Physiological					
22. Shivering ……	0	1	2	3	NA
23. Change in color, pallor ……..	0	1	2	3	NA
24. Sweating, perspiring ……..	0	1	2	3	NA
25. Tears……	0	1	2	3	NA
26. Sharp intake of breath, gasping……..	0	1	2	3	NA
27. Breath holding……	0	1	2	3	NA
VII. Eating/Sleeping					
28. Eating less, not interested in food……..	0	1	2	3	NA
29. Increase in sleep……	0	1	2	3	NA
30. Decrease in sleep…… ……..	0	1	2	3	NA

SCORE SUMMARY:

Category:	I	II	III	IV	V	VI	VII	TOTAL
Score:								

Case Based Discussion

Case 1: Daniel

- 60-year-old male with Down's Syndrome who lives in a group home
- Past Medical History significant for End-stage renal disease (hemodialysis), Hypertension, GERD and Anxiety
- Has had recent hospitalizations for PermCath dysfunction as well as sepsis admissions
- Recently discharged from hospital and had placement of PermCath after pulled out
- Called by group home to take Daniel back to hospital for re-insertion
- Daniel was calm and with no signs of agitation or irritability until EMS arrives on scene and he becomes agitated and distressed and pushing staff away.

What would you do now?

What resources are you aware of in your area?

What would you want to know about Daniel?

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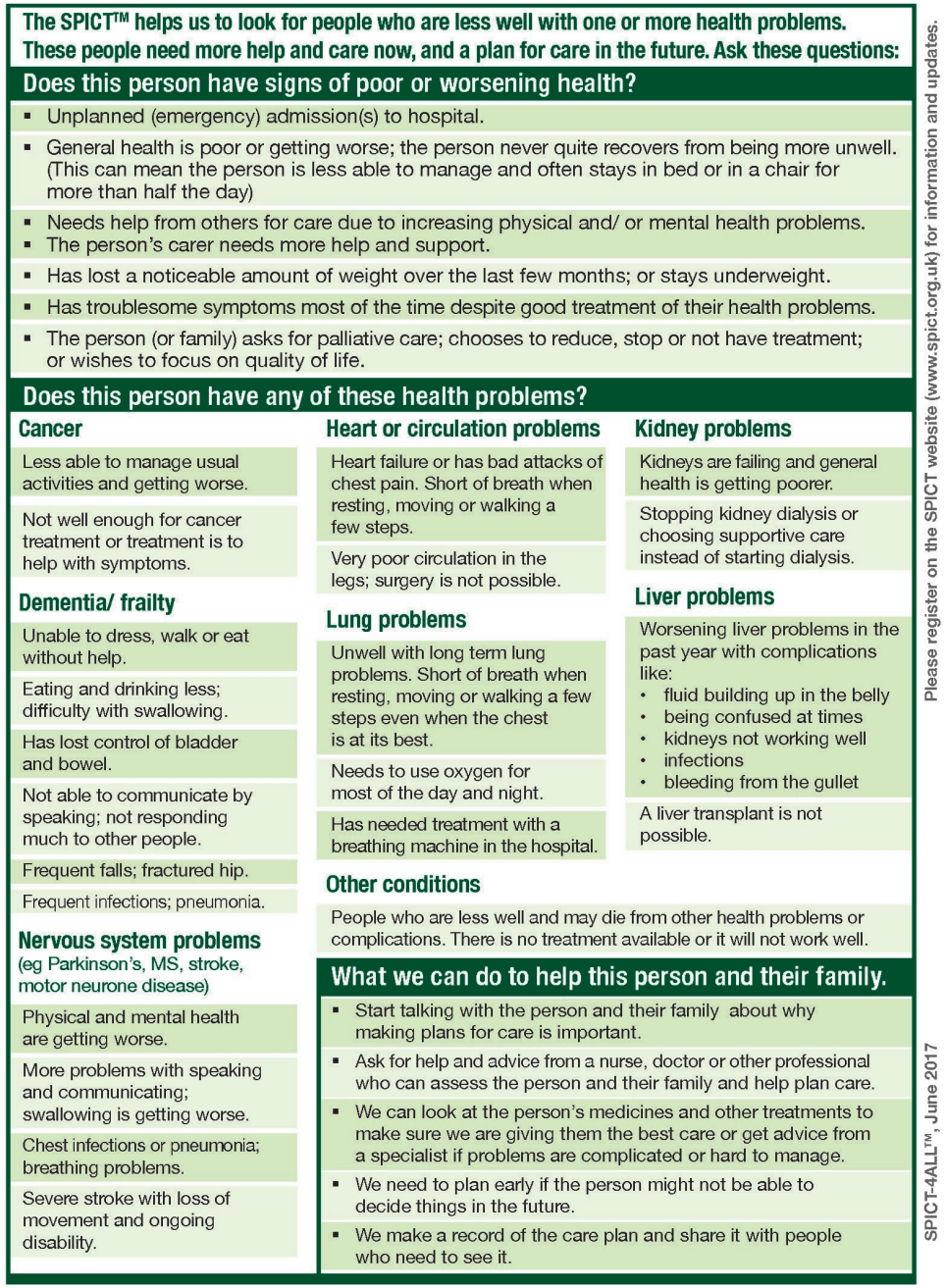
SPICT-4ALL



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Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

(eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

Project ECHO Palliative Care - Canada BY Pallium Canada

Daniel

- Last hospital admission required sedation to control agitation and distress
  - Normally in group home he is very calm and cooperative
- Requires moderate sedation for days he goes to dialysis
- Has pulled on his PermCath line on numerous occasions
- Has been losing weight, less interactive and sleeping during the day (almost 13 hours of sleep per day)

Case: Anjali

- 21-year-old female with global developmental delay, cerebral palsy and non-verbal living with parents
- Has been fine all week but has been shaking uncontrollably for the last 45 min
- Family called 911 for assistance and management

What do you want to know?

What are next steps?

What are some important questions to ask?

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Session Wrap-Up

- Please fill out our feedback survey! A link has been added to the chat.
- Join us for our next session about **Pain and Symptom Management** on **July 22, 2024 from 12-1pm ET.**

Thank You

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Appendix

- Palliative PALLI IDD
- SPICT-4ALL
- PAIN CPS NAID
- DIS DAT

Palliative PALLI ID

The PALLI questionnaire can help care providers to assess whether and to what extent **the health** of a person with intellectual disabilities (ID) **has deteriorated**. For people whose health has deteriorated and life expectancy is limited *palliative care** can be appropriate: care and support aimed at increasing comfort and quality of life.

The PALLI is concerned with health, behaviour and functioning of the person with ID compared with the previous period.
The PALLI, combined with your knowledge of the case history, can help you in timely deciding whether the care of the person should be refocussed in consultation with other parties involved. Our advice is **to discuss** the results of the PALLI in a **multidisciplinary** meeting and **consider** palliative care **together with all people involved**.

WHO IS THE PALLI FOR?
The PALLI can be completed for every **adult with ID**, regardless of the level and nature of disability. Due to this broad target group, some of the questions may not be relevant.

WHO COMPLETES THE PALLI?
The PALLI should be completed by **care providers who are familiar with the person with ID**. These may be daily care professionals, but physicians or other care providers may also complete the PALLI.

WHEN DO YOU COMPLETE THE PALLI?
- **'Gut feeling'**: For care providers, the PALLI can help in making concrete a gut feeling about a change in health and thereby facilitate discussion around this.
- **Consultation**: the PALLI can be completed before a person's regular (e.g. annual) personal review or care planning meeting, when specific plans around (for example) discharge to hospital or resuscitation need to be decided, or when specific questions arise around the palliative care needs for the person.

HOW DO YOU COMPLETE THE PALLI?
We would like you to cast your mind back to the **previous months** and consider whether there have been changes in health, behaviour or functioning of the person with ID. The guideline we apply is **3-6 months**; you can use another period if that seems more appropriate.

Every question can be answered with **'YES'** or **'NO'**. Please choose 'YES' or 'NO' even if you are in doubt. You can describe your reservations in the space for additional remarks. If you really do not know the answer and do not have information about it, please tick the question mark '?'.

In every category there is *'other (please specify)'*. Here you can **complement your answer**. We emphasise that the PALLI is a tool and that it does not necessarily give a complete picture.

You can complete the PALLI alone or together with others, with or without consulting the personal or medical file. There is no right or wrong answer; this is about your experience. Therefore, please do not think too long before answering. Completion time is approximately **10-15 minutes**.

* *Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems: physical, psychosocial and spiritual.* Palliative care can be considered early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy and radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

The PALLI has been made financially possible by:
Jan Jongmans Fonds, ds. Visscher fonds, stichting SFO

Radboudumc

Name(s) and position(s) of the person(s) who complete the PALLI: …….
……

Date of completion: …… / …… / ……

Name person with ID: ……
Date of birth of person: …… / …… / ……

Level of ID (if known): ……
Nature or cause ID (if known): ……

Physical

How are things going at the moment, when compared with the previous **3-6** months?

1. Does the person have a worse physical condition or is the person tired more quickly?	⌋ YES	⌋ NO	⌋ ?
2. Does the person spend more time in bed?	⌋ YES	⌋ NO	⌋ ?
3. Is the person more sleepy or drowsy?	⌋ YES	⌋ NO	⌋ ?
4. Is the person less able to move? (For example: more need for help with moving, more falls)	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Activities

How are things going at the moment, when compared with the previous **3-6** months?

5. Does the person take less initiative or is it more difficult to motivate him/her?	⌋ YES	⌋ NO	⌋ ?
6. Does the person more frequently decline to do or undertake things? (For example: getting out of bed, moving, daily activities, work, other activities)	⌋ YES	⌋ NO	⌋ ?
7. Is the person less able to perform activities in daily living (ADL) himself/herself, as a result of which daily caregivers need to do more?	⌋ YES	⌋ NO	⌋ ?
8. Are there any signs that the person does not manage daily activities or routines, work or other activities as well as before, as a result of which daily caregivers need to assist more?	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Questions? cis.vrijmoeth@radboudumc.nl / marieke.groot@radboudumc.nl

Characteristic behaviour

How are things going at the moment, when compared with the previous **3-6** months?

9. Does the person make more or less contact or does he/she make contact in a different way? (For example: responds differently to (the presence of) others, less talkative/communicative, trying to approach someone more often)	⌋ YES	⌋ NO	⌋ ?
10. Is the person more passive or apathetic? (For example: has become more docile, listless, less able or inclined to do things, reduced zest for life)	⌋ YES	⌋ NO	⌋ ?
11. Is the person more withdrawn? (For example: more need for peace and quiet, more easily overstrung)	⌋ YES	⌋ NO	⌋ ?
12. Does the person display more challenging or restless behaviour? (For example: more irritable, obstinate, aggressive or angry)	⌋ YES	⌋ NO	⌋ ?
13. Is the person more low in mood or depressed?	⌋ YES	⌋ NO	⌋ ?
14. Is the person more anxious?	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Statements

This concerns things that have been said during the previous **3-6** months.

15. Did the person say anything that indicated a change in health? (For example: *"I feel…", "I don't want… anymore", "I'm frightened…"*)	⌋ YES	⌋ NO	⌋ ?
16. Did family members/loved ones say anything that indicated a change in health? (For example: *"not feeling well", "he is not himself", "there's something going on", "he used to enjoy this, now he doesn't anymore")*	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Signs and symptoms

How are things going at the moment, when compared with the previous **3-6** months?

17. Has the person lost weight or is he/she becoming thinner?	⌋ YES	⌋ NO	⌋ ?
18. Has the person's food intake decreased? (For example: less appetite, cannot or doesn't want to eat as much, preference for a certain kind of food)	⌋ YES	⌋ NO	⌋ ?
19. Has the person's fluid intake decreased? (For example: cannot or doesn't want to drink as much, preference for certain drinks)	⌋ YES	⌋ NO	⌋ ?
20. Does the person have more problems swallowing?	⌋ YES	⌋ NO	⌋ ?
21. Does the person have more problems with bowel movements? (For example: constipation,diarrhoea)	⌋ YES	⌋ NO	⌋ ?
22. Does the person have more problems with nausea or vomiting?	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Questions? cis.vrijmoeth@radboudumc.nl / marieke.groot@radboudumc.nl

Signs and symptoms

How are things going at the moment, when compared with the previous **3-6** months?

23. Does the person show more (observable) signs of *unwellness*? (For example: (nocturnal) agitation, restless movements, facial expressions, noises made by the person, characteristic movements of discomfort)	⌋ YES	⌋ NO	⌋ ?
24. Does the person have more pain?	⌋ YES	⌋ NO	⌋ ?
25. Is the person more confused?	⌋ YES	⌋ NO	⌋ ?
26. Has the person's cognition deteriorated? (For example: remembers less, less orientated in time and place, loss of practical skills)	⌋ YES	⌋ NO	⌋ ?
27. Does the person have more sleep problems? (For example: problems falling asleep, problems staying asleep, changes in day/night rhythm)	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Signs and symptoms

How are things going at the moment, when compared with the previous **3-6** months?

28. Does the person have worse, or less well controlled, epilepsy?	⌋ YES	⌋ NO	⌋ ?
29. Does the person have worse spasticity?	⌋ YES	⌋ NO	⌋ ?
30. Is the person more dehydrated? (For example: less urine production)	⌋ YES	⌋ NO	⌋ ?
31. Does the person experience more shortness of breath? (For example: clearly audible breathing, faster breathing, difficulty breathing)	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Infections or episodes of fever

How are things going at the moment, when compared with the previous **3-6** months?

32. Does the person have recurrent infections or episodes of fever? (For example: pneumonia, cystitis, other infections or episodes of fever)	⌋ YES	⌋ NO	⌋ ?
33. Does the effect of antibiotics decrease with each infection or episode of fever?	⌋ YES	⌋ NO	⌋ ?
34. Does the person recover less well or have a longer recovery period after each infection or episode of fever?	⌋ YES	⌋ NO	⌋ ?

Other (please specify)…

Questions? cis.vrijmoeth@radboudumc.nl / marieke.groot@radboudumc.nl

Frailty

35. Are there several health problems that together increase the person's vulnerability to a (further) decline in health? ⌋ YES ⌋ NO ⌋ ?
(Health problems relate to psychical, psychological and social wellbeing)

Other (please specify)…

Disorders/illness

36. Is there a diagnosis or a strong suspicion of the existence of a serious (chronic) illness? ⌋ YES ⌋ NO ⌋ ?
(For example: dementia, lung diseases, cardiovascular diseases, diabetes, rheumatism or cancer etc.)

37. Is there a serious (chronic) illness that cannot be treated or for which treatment is not indicated (anymore)? ⌋ YES ⌋ NO ⌋ ?
(For example: there is no treatment or the treatment has no effect, the person doesn't respond to the treatment due to complications or side effects, treatment can't be carried out, or the treatment burden outweighs possible benefits for length or quality of life)

Other (please specify)…

Prognosis

38. Is there a shortened life expectancy and is the person approaching the end of life? ⌋ YES ⌋ NO ⌋ ?
(What is your assessment, perhaps based on changes in health or diagnosis of a serious (chronic) illness?)

39. Would you be surprised if this person were to die in the next 12 months? ⌋ YES ⌋ NO ⌋ ?
(This is *not* about whether you *expect* the person to die, but whether you'd be surprised if this person were to die within a year)

Other (please specify)…

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SPICT-4ALL

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Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

(eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Other conditions

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What we can do to help this person and their family.

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- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
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SPICT-4ALL™, June 2017

Project ECHO Palliative Care - Canada BY Pallium Canada

CPS-NAID

Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in *items 1-24* in the last 5 minutes.
Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

0 =	Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
1 =	Seen or heard rarely (hardly at all), but is present.
2 =	Seen or heard a number of times, but not continuous (not all the time).
3 =	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
NA =	Not applicable. This person is not capable of performing this action.

0 = Not at all	1 = Just a little	2 = Fairly Often	3 = Very Often	NA = Not Applicable

1. Moaning, whining, whimpering (fairly soft)	0	1	2	3	NA
2. Crying (moderately loud)	0	1	2	3	NA
3. A specific sound or word for pain (e.g. A word, cry or type of laugh)	0	1	2	3	NA
4. Not cooperating, irritable, unhappy	0	1	2	3	NA
5. Less interaction with others, withdrawn	0	1	2	3	NA
6. Seeking comfort of physical closeness	0	1	2	3	NA
7. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
8. A furrowed brow	0	1	2	3	NA
9. A change in eyes, including: squinching of eyes opened wide, eyes frowning	0	1	2	3	NA
10. Turning down of mouth, not smiling	0	1	2	3	NA
11. Lips puckering up, tight, pouting or quivering	0	1	2	3	NA
12. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA
13. Not moving, less active, quiet	0	1	2	3	NA
14. Stiff, spastic, tense, rigid	0	1	2	3	NA
15. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
16. Protecting, favouring or guarding part of body that hurts	0	1	2	3	NA
17. Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
18. Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)	0	1	2	3	NA
19. Shivering	0	1	2	3	NA
20. Change in colour, pallor	0	1	2	3	NA
21. Sweating, perspiring	0	1	2	3	NA
22. Tears	0	1	2	3	NA
23. Sharp intake of breath, gasping	0	1	2	3	NA
24. Breath holding	0	1	2	3	NA
Subtotals: 1. For each subtotal write the number of times each value was chosen	NA	1x___	2 x___	3x___	NA
2. Multiply the value of each selection by how many times that value was chosen 3. Add each subtotal to find the total score		=____	=____	=____	**Total:** ____

SCORING:

1. Add up the scores for each item to compute the Total Score. Items marked "NA" are scored as "0" (zero).
2. Check whether the score is greater than the cut-off score.
   A score of 10 or greater means that there is a 94% chance that the person has pain.
   A score of 9 or lower means that there is an 87% chance that the person does not have pain.

For more information see Burkitt, Breau et al., (2009). Pilot study of the feasibility of the Non-Communicating Children's Pain Checklist – Revised for pain assessment in adults with intellectual disabilities. *Journal of Pain Management*, 2(1). CPS-NAID © 2009 Breau, Burkitt, Salsman, Sarsfield-Turner, Mullan.