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 don't know the answer and don't 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 doesn't 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 don't 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

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 quicker? | ☐ YES | ☐ NO | ☐ ? |
| 2. Is the person more bedridden? | ☐ YES | ☐ NO | ☐ ? |
| 3. Is the person more somnolent or drowsy? | ☐ YES | ☐ NO | ☐ ? |
| 4. Is the person less able to move?<br>(For example: more need for help with moving, more falls) | ☐ YES | ☐ NO | ☐ ? |

Other (please specify)…

## Activities of Daily Living

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

| | | | |
|---|---|---|---|
| 5. Does the person take less initiative or is he/she less well to stimulate? | ☐ YES | ☐ NO | ☐ ? |
| 6. Does the person more frequently decline to do or undertake things?<br>(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 doesn't 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)…



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## 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?<br>(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?<br>(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?<br>(For example: more need for peace and quiet, more easily overstrung) | ☐ YES | ☐ NO | ☐ ? |
| 12. Does the person display more challenging or restless behaviour?<br>(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?<br>(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?<br>(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?<br>(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?<br>(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?<br>(For example: constipation, diarrhoea) | ☐ YES | ☐ NO | ☐ ? |
| 22. Does the person have problems with nausea or vomiting? | ☐ YES | ☐ NO | ☐ ? |

Other (please specify)…



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## 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*?<br>(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?<br>(For example: remembers less, less orientated in time and place, loss of practical skills) | ☐ YES | ☐ NO | ☐ ? |
| 27. Does the person have more sleep problems?<br>(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?<br>(For example: less urine production) | ☐ YES | ☐ NO | ☐ ? |
| 31. Does the person experience more shortness of breath?<br>(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?<br>(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)…



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## Frailty

35. Are there several health problems which 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 can't be treated or for which treatment isn't 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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