CHAPTER 9

INDIVIDUALIZED ADVANCE CARE PLANNING IN CHILDREN WITH LIFE-LIMITING CONDITIONS

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9.1 ABSTRACT

INTRODUCTION
In 2013, the Pediatric Association of the Netherlands launched an evidence-based guideline “Palliative care for children”. To promote implementation in daily practice and hereby improve quality of pediatric palliative care, we aimed to develop a functional individualized pediatric palliative care plan (IPPCP) that covers physical, psychological, spiritual and social functioning, with great emphasis on the guideline’s recommendations, advance care planning and patients’ and parents’ preferences and desires.

METHODS
A Dutch working group (28 individuals) with a strong multidisciplinary character developed a draft IPPCP, which was piloted retro- and prospectively. In the pilots we completed the IPPCPs for patients who were recently diagnosed with a life-threatening or life-limiting condition and evaluated completeness, usability and user-friendliness.

RESULTS
The final IPPCP comprised five domains: 1) IPPCP data, 2) basics, 3) social, 4) psychosocial and spiritual, and 5) physical care. Each domain covered various components. In both pilots, the IPPCP was considered a comprehensive document that covered all areas of pediatric palliative care, and was experienced as an improvement to the present situation. However, the current form was regarded to lack user-friendliness.

CONCLUSION
We propose a set of essential components of a comprehensive IPPCP for pediatric palliative care with extra attention for advance care planning and anticipatory action. Patients’ and parents’ preferences and desires are included next to the recommendations of the evidence-based guideline “Palliative care for children”.
9.2 INTRODUCTION

In the Netherlands, every year nearly a thousand children (aged 0–15 years) die and an estimated five-fold of this number are confronted with a life-threatening or life-limiting condition.[1,2] These children deserve high quality palliative care, which according to the WHO comprises “the active total care of the child’s body, mind and spirit, and also involves giving support to the family”.[3]

Palliative care can be misinterpreted as care in the palliative-terminal phase. For instance, children with profound multiple disabilities have a vulnerable health and sometimes extensive underlying suffering. Palliative care in these children should be provided well before the terminal (end-of-life) phase.

Recently in pediatric palliative care, there has been growing interest in advance care planning (ACP), which is a multi-disciplinary, structured process that puts great emphasis on patient and family preferences, and encourages discussion of possible scenarios with the child and his/her parents in an early stage.[4] Perceived benefits of ACP include better quality of care, respect of patient autonomy, and a sense of security and control.[5] In a randomized trial in elderly patients use of ACP improved end-of-life care and satisfaction of patient and family, and reduced stress, anxiety, and depression in surviving relatives.[6] Important aspects of effective implementation of ACP include e.g. timely planning and continuous discussions, taking into account all aspects of palliative and end-of-life care (without losing focus on everyday aspects of life as well), involvement of all relevant professionals, and structural education.[5]

In recently published international guidelines, the need for ACP is acknowledged. For instance, in the American Academy of Pediatrics endorsed 2013 guideline entitled “Clinical Practice Guidelines for Quality Palliative Care”, ACP is stated explicitly as preferred practice.[7] Also, specifically in children, detailed documentation of the child’s views and preferences is encouraged. These sentiments are mimicked in (pediatric) palliative care guidance documents in other parts of the world, for instance in the UK (NICE, 2016) and in New-Zealand (NCYCN, 2015).[8,9]

In 2013, the Paediatric Association of the Netherlands was among the first to launch a multidisciplinary, evidence-based guideline focusing solely on pediatric palliative care. [2,10] Despite previous efforts, it is our experience that this guideline is not yet optimally implemented.[11] We ambition better implementation, since evidence-based guideline compliant care has been repeatedly shown to improve patient outcomes and efficient care delivery.[12,13]
Naturally, a limitation of all guidelines is the fact that they are not tailored to a specific patient, but merely advise on the average patient. An individualized care plan contains information, agreements, advices for symptom management, including personal wishes, tailored to a specific patient. It is therefore a highly suitable instrument to translate a guideline into practice. When compared to usual care, the use of an individualized care plan has shown to improve indicators of health status, and promotes the capability of patients to self-manage their condition.[14]

An individualized care approach for children with a life-threatening or life-limiting condition has the potential to contribute to consistent high-quality pediatric palliative care in which all essential areas are explored. In this study, we aimed to develop and test a functional and comprehensive individualized pediatric palliative care plan (IPPCP). This IPPCP is based on both the recommendations of the guideline “Palliative care for children” and on expert-knowledge, is in line with the WHO principles for pediatric palliative care, and puts great emphasis on ACP and patients’ and parents’ preferences and desires. In addition, it guides the healthcare provider, along with the patient and his/her family, in a structured manner to address all aspects important to pediatric palliative care (planning).

9.3 METHODS

DEVELOPMENTAL PROCESS

For a detailed flow diagram of the developmental process see Figure 9.1.
Figure 9.1. Flow diagram portraying the development of the IPPC
IPPCP = individualized pediatric palliative care plan
Initially a project group was created that comprised professionals involved in pediatric palliative care and parents of different children who had received palliative care (see Table 9.1). Group members were recruited via existing Dutch pediatric palliative care teams and patient/parent organizations. Several meetings for the entire project group were organized to discuss characteristics and components of the IPPCP.

Table 9.1. Involved professionals

<table>
<thead>
<tr>
<th>Core group</th>
<th>Working groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatrician specialized in palliative care</td>
<td>PHY / PSY</td>
</tr>
<tr>
<td>Pediatric oncologist</td>
<td>PHY</td>
</tr>
<tr>
<td>Pediatrician trained in epidemiology</td>
<td>PHY</td>
</tr>
<tr>
<td>Pediatrician</td>
<td>PHY / PSY</td>
</tr>
<tr>
<td>Director non-profit pediatric palliative care organization</td>
<td>PSY</td>
</tr>
<tr>
<td>Director pediatric home care organization</td>
<td>PHY</td>
</tr>
<tr>
<td>Board member pediatric nurse organization</td>
<td>PHY</td>
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<tr>
<td>PhD student pediatric oncology</td>
<td>PHY / PSY</td>
</tr>
<tr>
<td>Project group</td>
<td></td>
</tr>
<tr>
<td>Parent of a deceased girl</td>
<td>PHY</td>
</tr>
<tr>
<td>Parent of a deceased boy</td>
<td>PSY</td>
</tr>
<tr>
<td>Pediatric oncologist</td>
<td>PHY</td>
</tr>
<tr>
<td>Pediatric oncologist</td>
<td>PHY / PSY</td>
</tr>
<tr>
<td>Pediatrician specialized in hereditary and congenital diseases</td>
<td>PHY</td>
</tr>
<tr>
<td>Pediatric intensive care unit nurse</td>
<td>PHY</td>
</tr>
<tr>
<td>General practitioner</td>
<td>PHY / PSY</td>
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<tr>
<td>Pediatric nurse</td>
<td>PHY</td>
</tr>
<tr>
<td>General pediatrician</td>
<td>PHY</td>
</tr>
<tr>
<td>Staff member non-profit pediatric oncology organization</td>
<td>PSY</td>
</tr>
<tr>
<td>Staff member non-profit pediatric palliative care organization</td>
<td>PSY</td>
</tr>
<tr>
<td>Child life specialist</td>
<td>PSY</td>
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<tr>
<td>Spiritual caretaker</td>
<td>PSY</td>
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<tr>
<td>Proofreaders</td>
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<tr>
<td>Pediatric oncologist</td>
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<tr>
<td>Hospital pharmacist</td>
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<tr>
<td>Pediatric neurologist</td>
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<td>Pediatric critical care specialist</td>
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<td>Pediatric pulmonologist</td>
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<tr>
<td>Pediatric anesthetist</td>
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<tr>
<td>Physician assistant specialized in pediatric pain</td>
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</tbody>
</table>

PHY = working group focusing on physical aspects of pediatric palliative care,  
PSY = working group focusing on psychosocial aspects of pediatric palliative care
Early in the process a pragmatic decision was taken to divide the workload by sectionalizing the project group in a working group focusing on physical aspects of palliative care, and a working group focusing on psychosocial aspects.

The working group on physical aspects used the guideline “Palliative care for children” as basis for the development of the somatic part of the IPPCP. Recommendations were integrated per symptom as well as for overarching themes (e.g. nutrition).

The psychosocial working group aimed to developed specific recommendations for social, psychological, spiritual and logistical aspects of the various phases of palliative care. As the guideline “Palliative care for children” provides few evidence-based recommendations for particularly psychosocial and spiritual aspects, most of the recommendations from the psychosocial working group were based on shared expert opinion.

**SUPPORTING MANUAL**

We decided to create a comprehensive IPPCP form including personalized recommendations based on the guideline and a separate supporting manual including all recommendations and explanatory information. The manual was drafted by one researcher (EL), whereafter it was proofread repeatedly by the entire project group and adjusted according to their comments. Recommendations were categorized as *guideline* or *expert opinion*, and as do, consider or don’t. Before finalization, the manual was checked by one external reviewer for agreement with the recommendations of the guideline “Palliative care for children”.

**RETROSPECTIVE PILOT**

To pilot the IPPCP’s usability and completeness, we tested the form retrospectively. We asked three pediatricians with extensive experience in palliative care, and who were the responsible physician of a recently deceased child to complete an IPPCP as if it was at the start of the palliative course. We then asked them to recall the palliative course and evaluate if there were things missing, unusable or superfluous in the present form. We discussed this one on one in a telephone meeting where a researcher (EL) took notes, and discussed these with the project group. This yielded several valuable small additions (e.g. addition of ‘via nasogastric tube’ in way of administration of anti-emetic drugs), changes (e.g. pain ladder divided and arranged into more clinically logical steps), and deletions (e.g. duplicate items in different locations).
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PROSPECTIVE PILOT
Secondly, we did a prospective pilot which lasted two months and was commenced in five Dutch pediatric hospitals; Emma Children’s Hospital (Amsterdam), Beatrix Children’s Hospital (Groningen), Willem-Alexander Children’s Hospital (Leiden), Sophia Children’s Hospital (Rotterdam), and Princess Maxima Center for Pediatric Oncology (Utrecht). Pediatricians with experience in palliative care were invited to complete an IPPCP for a patient and his/her family with a recently diagnosed life-threatening or life-limiting condition. The IPPCP was completed together with the patient and his/her family prior to discharge to home. After completion, we asked the pediatricians to anonymize the IPPCP and send it to us.

We also invited them to complete an online survey, developed by a consensus-based approach in the core group, that explored section-wise ease of use and completeness, overall completeness, usability and change as compared to the current situation, and invited them to give overall comments and suggestions for the current IPPCP (see Supplemental material 9/S1). Scores were given on a 5-point Likert scale, e.g. ‘completeness’ was rated from one (very incomplete) to five (very complete). Group scores were categorized as ‘low’ (median 1-2), ‘average’ (median 2.5-3.5) or ‘high’ (median 4-5). For analysis purposes, we asked respondents to state their profession and the patient’s age, diagnosis and estimated life expectancy (classified as weeks, months, years or unclear).

IDENTIFICATION OF ESSENTIAL COMPONENTS
After incorporation of the feedback from both pilots, the core group evaluated the IPPCP and identified the components and domains for individualized care planning in pediatric palliative care.

ETHICAL APPROVAL
As this study concerned an improvement of care pilot in parallel to standard care and all data were obtained anonymous, neither approval of a medical ethical committee nor written informed consent was required.

9.4 RESULTS

This project lasted from October 2014 to December 2015. We chose to develop first an editable Word file (Microsoft Word 14.0, Microsoft, Redmond, Washington, USA), supported by a manual.
PHYSICAL ASPECTS
For all symptoms, a section was created with questions that the care provider and patient/parents could complete (e.g. “What is the goal regarding pain management?” and “First step pharmacological anti-emetic management”), supported by a short manual incorporating recommendations from the guideline and practical matters such as first-choice medication. Also, there were separate sections for medication, nutrition, and for complementary therapies and relaxation/wellness.

PSYCHOSOCIAL ASPECT
This working group developed a five phase model of pediatric palliative care, based on the health report regarding palliative care published in 2013 by the Dutch government. [15] These phases are 1) breaking bad news, 2) life continues – despite the bad news – relatively ‘normally’, 3) increase in symptoms (pre-terminal), 4) palliative-terminal phase, and 5) (bereavement) follow-up care. For all applicable phases, this working group developed separate recommendations for the patient, siblings, parents, close family and relatives, school, sports club, treating physician, general practitioner, pediatric home care nurses, and other involved care professionals.

SUPPORTING MANUAL
The 42-page manual guides the reader step by step through the various sections of the IPPCP, while providing concise background information, recommendations and other tips/advice.

PROSPECTIVE PILOT
Nine patients were included, diagnoses were brain tumor (n=3), DNA repair-deficiency disorder (n=2), peroxisomal disorder (n=2), congenital heart disease (n=1), or unknown (n=1). Median age was 10 years (range: 0–17 years), estimated life expectancy was unclear in five patients, ‘years’ in two patients and ‘weeks’ in two patients.

For the IPPCP in general, median scores were high for ‘completeness’ and ‘change compares to current situation’ and average for ‘ease of use’ and ‘usability in daily practice’ (see Table 9.2). The manual scored high for ‘completeness’, ‘change compared to use of guideline’ and ‘worthwhile addition to IPPCP’, and average for ‘amount of information’. All separate IPPCP sections had average to high scores for both ‘ease of use’ and ‘completeness’.

Professionals showed differences in comments and attitudes towards the IPPCP and manual. Generally, in the overall comments it was emphasized that the IPPCP was
very complete and useful, promoted collaboration and forced the user to anticipatory planning and action. However multiple professionals felt that the present form lacked user-friendliness, and suggested this could be improved by creating a fully digital and responsive version of the IPPCP.

Table 9.2. Scores of the prospective pilot.

<table>
<thead>
<tr>
<th>Item*</th>
<th>n</th>
<th>Median</th>
<th>Range</th>
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</thead>
<tbody>
<tr>
<td>Basics</td>
<td></td>
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</tr>
<tr>
<td>Ease of use</td>
<td>9</td>
<td>3</td>
<td>3</td>
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<tr>
<td>Completeness</td>
<td>9</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Social / psychosocial</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Ease of use</td>
<td>9</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Completeness</td>
<td>9</td>
<td>4</td>
<td>2</td>
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<tr>
<td>Needs, wishes, goals</td>
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<tr>
<td>Ease of use</td>
<td>9</td>
<td>3</td>
<td>3</td>
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<tr>
<td>Completeness</td>
<td>9</td>
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<tr>
<td>Medication and nutrition</td>
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<tr>
<td>Ease of use</td>
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<td>3</td>
<td>4</td>
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<tr>
<td>Completeness</td>
<td>7</td>
<td>4</td>
<td>3</td>
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<tr>
<td>Symptomatology</td>
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<tr>
<td>Ease of use</td>
<td>8</td>
<td>3.5</td>
<td>4</td>
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<tr>
<td>Completeness</td>
<td>8</td>
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<td>2</td>
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<tr>
<td>Complementary care / wellness</td>
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<tr>
<td>Ease of use</td>
<td>9</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Completeness</td>
<td>8</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>IPPCP - General</td>
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</tr>
<tr>
<td>Ease of use</td>
<td>9</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Completeness</td>
<td>9</td>
<td>5</td>
<td>3</td>
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<tr>
<td>Usability</td>
<td>9</td>
<td>3</td>
<td>4</td>
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<tr>
<td>Change compared to current situation</td>
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<tr>
<td></td>
<td>9</td>
<td>4</td>
<td>4</td>
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<tr>
<td>Manual</td>
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<td>4.5</td>
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<tr>
<td>Completeness</td>
<td>8</td>
<td>4.5</td>
<td>2</td>
</tr>
<tr>
<td>Amount of information</td>
<td></td>
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<tr>
<td>Change compared to use of guideline</td>
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<tr>
<td>Worthwhile addition to IPPCP</td>
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</table>

* All scoring items ranged from 1 to 5. For ease of use, this was from ‘very bad’ (1) to ‘very good’ (5), for completeness this was from ‘very incomplete’ (1) to ‘very complete’ (5), for usability this was from ‘very unusable’ (1) to ‘very usable’ (5), for change compared to current situation this was from ‘major worsening’ (1) to ‘major improvement’ (5), for amount of information this was from ‘too little information’ (1) to ‘too much information’ (5), for change compared to use of the guideline this was from ‘very negative change’ (1) to ‘very positive change’ (5), for worthwhile addition to IPPCP this was from ‘very unworthy addition’ (1) to ‘very worthwhile addition’ (5).
IDENTIFICATION OF ESSENTIAL COMPONENTS
After incorporating the feedback from the prospective pilot, which lead to similar small additions, changes and deletions as the retrospective pilot did, the project core group discussed and finalized the IPPCP. The final IPPCP consisted of five domains; 1) IPPCP data, 2) basics, 3) social, 4) psychosocial and spiritual, and 5) physical (Figure 9.2). These domains included a total of 32 components that were integrated in the IPPCP in 10 sections.

EXAMPLE IPPCP
An example of a partially completed IPPCP for a fictional patient can be found in Supplemental material 9/S2.

Figure 9.2. Contents of the IPPCP
ICP = individualized care plan, IPPCP = individualized pediatric palliative care plan
9.5 DISCUSSION

With this study care providers and parents have identified a set of components that are essential for an individualized pediatric palliative care plan that facilitates high-quality care (and transition of care from hospital to home). In this IPPCP we integrated recommendations from the Dutch evidence-based guideline “Palliative care for children” and recommendations from experts on physical, psychological, spiritual and social functioning. With the emphasis on the facilitation of ACP and the patients’ and parents’ preferences and desires, we believe this IPPCP is the pivotal next step in high-quality pediatric palliative care.

The IPPCP together with the manual will help to implement the aforementioned Dutch guideline “Palliative care for children”. Care in line with evidence-based guidelines has repeatedly been shown to improve outcomes, which we also suspect it will do in pediatric palliative care.[12,13] Therefore, putting the available scientific knowledge and recommendations in the hands of the practitioner and the patients and parents should be one of the cornerstones of contemporary medicine.

Implementation of an evidence-based guideline should not be limited to simple dissemination. In fact, a systematic review focusing on implementation strategies found this to be consistently ineffective.[16] Among other things, multifaceted interventions, patient-specific interventions and clinical reminders / decision support systems were found to be effective implementation strategies. An individualized care plan (ICP) exploits these processes to put a guideline into daily practice. Currently the IPPCP is already used in several hospitals and specialized pediatric palliative home care teams, and parent support groups have started to actively promote its use among their members. Hereby more first line professionals (e.g. general practitioners, home care teams) will be familiarized with the IPPCP and thus the guideline, making it an important driver of implementation. This implementation strategy is not limited to the field of palliative care per se. We believe that also in for example complex chronic diseases an ICP can function as a guideline implementation tool.

In a recent study in the United Kingdom, authors found that in 1 in 4 children with a life-threatening or life-limiting condition there was no advanced care plan, and almost half of all patients and their families were not offered a choice regarding location of care in the last months of life and location of death.[17] The lack of this advanced care plan, implies important decisions might be made later, on an ad hoc basis and the risk of time and/or emotional pressure. This underlines the importance of timely and structured ACP.
The IPPCP that we developed is comprehensive and was perceived by professionals as an improvement to the current situation especially due to its completeness, nevertheless users complained it lacks user-friendliness in the current form. This study can be considered as an essential first step. In a subsequent project we will develop a fully digital and responsive version of the IPPCP (with integrated manual). We believe this will improve user-friendliness substantially without compromising on the current strong points.

In the current project we merely evaluated post-development, which sometimes resulted in the identification of errors/impracticalities we could have identified beforehand. Thus, prior to developing the next version we plan to conduct a more thorough pre-evaluation of preferences and experiences of people involved in the field of pediatric palliative care, using semi-structured interviews. With this we expect to better map the barriers and facilitators of both healthcare providers and parents and patients when using the IPPCP. Combining these findings with a longer and more systematic pilot phase of the next IPPCP has the potential to substantially increase its value in daily practice.

**9.6 CONCLUSION**

In conclusion, with this study we have identified a set of essential components of a comprehensive IPPCP, that 1) covers all aspects of pediatric palliative care, 2) puts great emphasis on advance care planning and anticipatory action, 3) actively seeks and integrates patients’ and parents’ preferences and desires, and 4) incorporates recommendations of the Dutch evidence-based guideline “Palliative care for children”. In addition we demonstrated that an ICP is a promising method for nationwide implementation of an evidence-based guideline and management of complex care, which can be mimicked in other fields. Because although we are focusing on pediatric palliative care, the concept of advance care planning relates very well to the care for all children with chronic complex illnesses.

**ACKNOWLEDGEMENTS**

The project “Development of an individualized pediatric palliative care plan” is supported by a grant of the Netherlands Organisation for Health Research and Development (ZonMW, project number 626006007). We thank LMAJ Venmans for carefully checking the manual for possible conflicts with the recommendations in the guideline “Palliative Care for Children”. Special thanks go to the patients and parents involved in the pilots, and to the parent-experts participating in the working group.
SUPPLEMENTAL MATERIALS
The following supplemental materials are available, 9/S2 is included below, 9/S1 is available online:

9/S1  Survey of the prospective pilot (3 pages)
9/S2  Example case and partially completed ICP (4 pages)
9.7 REFERENCES


9.8 SUPPLEMENTAL MATERIALS

Supplemental material S9/2.
Example case and partially completed ICP

Case
Jack is a 7-year-old boy with cerebral palsy and a profound intellectual disability, which originated from a post anoxic encephalopathy. He is wheelchair-bound, not able to communicate verbally, and receives nutrition and fluids via a PEG tube. Jack lives in a specially adapted dwelling together with his parents and 4-year-old sister. He has been admitted to the hospital 3 times last year, which was related to respiratory problems that he frequently experiences. His care at home comprises: daily nebulization of an inhalation steroid, ipratropium bromide/salbutamol if needed, oxygen if needed, physiotherapy for sputum mobilization. Both his parents and his sister are aware that Jack won’t become very old. They enjoy the time they have with each other, in which they like to take Jack for a long walk, listen to music and hug each other. This case illustrates a typical patient of whom there is no direct expectation of a rapidly approaching end-of-life phase, but is very suitable for completing an ICP for pediatric palliative care. Children with profound multiple disabilities have a vulnerable health and often extensive underlying suffering. Palliative care in these children is not limited to the palliative-terminal (end-of-life) phase. By completing an ICP one can anticipate optimally on expected (and as much as possible on unexpected) issues in this long palliative course.

ICP
NB. This example only contains some elements of the ICP: sentences are aborted with [...] and deleted elements are indicated with

1. ICP Data
This care plan
--/--
- Is agreed on by child (always when 12+): Not applicable
  on: Select date
- Is agreed on by parents on: August 1st 2016
- Is agreed on by the responsible physician on: August 1st 2016
- Will be revised on: February 1st 2017

2. Basics
--/--
Medical situation
- Diagnosis - cerebral palsy and a profound intellectual disability, originating from a post anoxic encephalopathy
- Date of diagnosis – June 15th 2008
- Severity / prognosis:
  Shortened life expectancy, extremely hard to quantify. Probably years but due to high risk of airway complications there is also a chance on early death. Wheelchair-bound, verbal communication not possible. Nutrition and fluids via a PEG tube.
- Relevant medical history:
--/--
CHAPTER 9

<table>
<thead>
<tr>
<th>Care providers</th>
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<tbody>
<tr>
<td><strong>24/7 emergency number</strong></td>
</tr>
<tr>
<td><strong>Responsible Physician</strong></td>
</tr>
<tr>
<td>Tel.</td>
</tr>
<tr>
<td><strong>Outside office hours</strong></td>
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<tr>
<td><strong>Case manager</strong></td>
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<tr>
<td>Tel.</td>
</tr>
<tr>
<td><strong>Outside office hours</strong></td>
</tr>
</tbody>
</table>

3. Social map/ psychosocial anamnesis

**Family information**
- **Family**
  - Father: Tim, 37 years, works 2 days a week as a longshoreman
  - Mother: Simone, 34 years, works 2 days as a kindergarten teacher
  - Siblings: Sister, Sonya, 4 years, healthy, loves to play with Jack
- **Living circumstances**
  Adjusted, one-floor dwelling. In the toilet and the bathroom are special adjustments […]

**Perception**
- **Important aspects in the perception**
  Family is not religious. They are seeking meaning together with a mental caretaker […]

4. Needs, wishes, goals

What are the personal wishes, expectations, needs and (general) goals of the child?
Jack enjoys being outside. Although he cannot explicitly state his wishes, his parents think Jack finds it important to be able to keep going on long walks with his parents and sister. Jack can panic easily whenever he is dyspnoeic, therefore it is important to […]

**Limitations of treatment**

Yes. Parents are well aware that things can deteriorate quickly and unexpectedly.
- **Resuscitation**
  - Circulation; pharmaceutical support: No
  - Ventilation; mucus suction: Only for comfort
  - Ventilation; bag-valve-mask: No
- **Admission to Intensive Care Unit**
  Depends on the conditions

**End-of-life**
- **Important aspects**
  Jack is more relaxed at home than in the hospital, […]
- **Possible obduction / donation**
  Not yet discussed.
- **Farewell and funeral**
  Depends on age, parents want music that […]
- **Bereavement care**
  Mental caretaker will stay involved after Jack’s death.
5. Medication
Daily / weekly
Budesonide/formoterol 2 dd [...] 

6. Nutrition
Agreements regarding fluids, nutrition and supplements
Next to the planned nutrition and fluids Jack can also indicate when he […] 

7. Symptomatology
7a. PAIN
Current situation: No pain
Expectation / “Will this symptom likely occur in the palliative course?”:
Not very likely, except during periods of respiratory problems (e.g. pneumonia).

Goal child / parents:
Jack panics quickly when he experiences pain, therefore parents find it extremely important that he has as little pain as possible, even when effectively treating the pain has some drowsiness as side-effect.

Treatment – Pharmacological
Nociceptive pain
Currently in step: 0 , additions/adjustments: currently none
Step 1 – non opioids
Step 1a - Acetaminophen (dosage link)
Dose: Acetaminophen 24 mg/ml, 3 dd 240 mg.
Form of administering: Suspension via PEG tube
Step 1b – NSAIDs (dosage link)
Dose: Ibuprofen 20 mg/ml, 3 dd 100 mg.
Form of administering: Suspension via PEG tube

8. Complementary / alternative care (CAM) and relaxation / wellness
Actions regarding relaxations / wellness
Jack enjoys light piano music, it calms him. When Jack is dyspnoeic, parents adjust the wheelchair so that he […] 

9. History of changes
Last update on: August 1st 2016

10. Other
When composing and discussing this care plan with parents they brought forward that […] 
