

STEP Newsletter

February

STEP UPDATE

STEP is a one-year pilot (ending mid-2019) aiming to improve the quality of life of both caregivers and their children with Cerebral Palsy (CP) in the home situation. For more information, you may visit our online platform (<https://connect.lilianefonds.org/step/default.aspx>) or email Léa Guignard (Jr. Project Manager): lguignard@lilianefonds.nl

The pilot has entered into its last phase, which consists of:

- Continued coaching of fieldworkers, with Petra van Kampen in Cameroon during February, and Kenneth and Kees in the Lake Victoria Region from January to April. During this period, more emphasis will be put on discussing with the management of (S)POs how to proceed after finishing the pilot.
- A final workshop will be held in Kampala, from April 3 to April 5. The goals of the workshop will be to:
 - discuss with participating (S)POs how to possibly embed this new approach within their regular programmes; and
 - discuss with potential (external) stakeholders how to form necessary partnerships.

On the final day, training sessions for fieldworkers will be given about specific subjects. A report of this event will be shared in May 2019.

- Collecting evidence on results is an important element in the STEP-pilot. For this reason, preparations are being made for:
 - qualitative research, based on 11 case studies (Angelique Kester, Enablement); and
 - an end-evaluation, which will be done by an external evaluator. More news on process and publications will be in the next STEP Newsletter, which is scheduled for May/ June 2019.

INTRODUCTION: A SPECIAL EDITION ON 'EXERCISES'

Health professionals and rehabilitation centres are very important for STEP fieldworkers to partner with in addressing the needs of children with CP and of their caregivers. Professionals, like physiotherapists and occupational therapists, are trained to do proper assessments and set relevant goals. However, a common practice among health professionals in the management and handling of children with CP is mainly 'therapy', with routine exercises: passive stretching, often combined with the use of callipers.

The aim of this special edition is to start a debate about this practice, which can often be harmful, and to ask ourselves whether there are and if so, which, alternative interventions we have.

In this special, you will read more about *the importance of integrating exercises into functional daily activities, with a specific role for STEP fieldworkers to coach caregivers on **why and how** to do this in a meaningful way.*

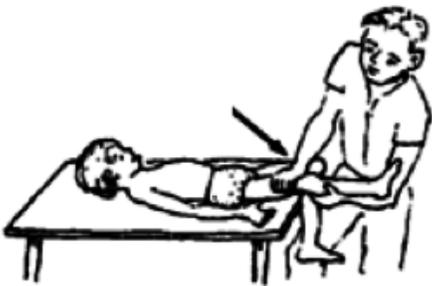
We welcome any comments and look forward to receiving your feedback.



Stretching FOCUS

TO STRETCH OR NOT TO STRETCH, THAT IS THE QUESTION TO BE ANSWERED HERE

In this special edition, we want to address a subject that is not a specific goal of the STEP approach but something we encounter often as the main intervention: stretching of the limbs. Stretching is not the same as functional activities. In the STEP approach we focus on functional improvement, enabling children with Cerebral Palsy to do more in daily life, increasing well-being, and helping caregivers on *how* to care for their child with a disability. Passive stretching is often advised and practiced in the treatment of children with CP, with caregivers being asked to come to the hospital for treatment before continuing this at home.



They thus think this helps improve their child's functioning, although this does not always hold true. This may result in frustration of caregivers. Additionally, fieldworkers are often taught these

passive exercises in training and perform these with the child at home. This practice is costly in terms of time and money and does not always have the intended positive effects on the child's functioning.

STEP is aimed at improving the quality of life of children with Cerebral Palsy living at home. This means something different for each child and caregiver. For example, reducing epilepsy might improve the quality of life for one family. Other caregivers might want their children to be able to eat themselves, sit independently, play with friends or be able to walk and go to school. Except for epilepsy, all the other goals are directed at the activity- and participation-levels, and not on the level of body functions and structures. Improvement in the anatomy of the body is not automatically improving a child's ability to perform certain activities. Personal factors (such as habits and how the child copes with certain difficulties) and environmental factors (such as the accessibility of the house) also play a role in the development and functioning of a child. Thus, passive stretching *by itself*, which solely targets the body functions and structures level, will not improve the child's functioning.

THINGS TO KEEP IN MIND

- Passive manual stretching also used to be common practice in Western countries, but scientific evidence has shown it has no long-lasting effect and children mostly don't like it. It *hurts* them and when they start *crying*, their *muscle tone increases*, having the opposite effect of what stretching aims to achieve in the first place.
- What has been proven to be effective (on the body functions and structures level) is passive stretching *with* the assistance of orthotics (callipers), when they are applied for 6-8 continuous hours a day. This, however, requires a lot of attention in order to gradually build up towards this duration. In addition, children may have difficulty

sleeping when using them at night and are at risk of developing pressure sores when orthotics are not used properly.

- Stretching (passive or active) is only useful when there is a risk of developing contractures that *limit* a child in doing activities. A child that is floppy will not develop limiting contractures. Mostly, children with involuntary movements will also not develop contractures that limit them in their activities. This only leaves children with stiffness (spasticity), in which case stretching may be considered, although *only* if it will help the child in doing activities better, decrease pain or render taking care of the child easier.
- The only reasons to try to keep some joints from contracting too much are:
 - Proper sitting: knee contractures of more than 90 degrees make comfortable and active sitting more difficult.
 - Scissoring of the legs: when the legs are scissoring, it is difficult to maintain good hygiene of the genital region. Also, spreading the legs is important for having a certain amount of balance when sitting.
 - Hip-, elbow- and finger-contractures: too severe contractures may cause problems with hygiene.



ADVICE FOR INTERVENTION



- Your interventions should be aimed at activities that are useful, meaningful and motivating for the child. With such activities, children can also be actively stretching their joints, so no passive stretching is needed.
- When contractures are limiting the activities that a child can do or cause problems in the care of a child, stretching of muscles needs to be done over a longer period of time with assistive devices. Examples are an abduction wedge in a (wheel)chair (see picture on the outermost left), or in bed to keep legs from scissoring, a rolled-up towel in the hand to prevent fungus from accumulating in the hand- or palm-folds, etc.

- In the case of orthotics referrals, clearly indicate to caregivers the purpose of the orthotics and how to use them.
- In children with mild- to moderate-CP, treating contractures with surgery may be an option if it leads to improvement in functioning. Serial casting of the feet can also improve balance in standing and walking in mild- and moderate-CP.

TAKE HOME MESSAGES

1. When you feel that the advised passive stretching exercises will not be useful and perhaps even harmful to the child, talk to the caregivers and health workers about it. This will save the caregivers money, time, and in the end, frustration and guilt.
2. Passive, manual stretching is not effective on its own: neither in improving the straightening of a joint in the long run nor in improving activities.
3. Passive stretching is only useful when:
 - a. Contractures limit the ability to perform activities or cause pain.
 - b. Contractures make the care and hygiene of the child more difficult.
 - c. Administered 6-8 hours a day without disturbing sleep, health, and well-being of the child.

Acknowledgment

Contribution from Angelique Kester, Huib Cornielje, Kees van den Broek, Petra van Kampen

References

Werner, D. (2018). *Disabled Village Children: A guide for community health workers, rehabilitation workers, and families*. Palo Alto, California: The Hesperian Foundation.

