

# Rare healthcare transition model

**National alliance of rare disease patient organisations**

**[www.sallsyntadiagnoser.se/verksamhet/overgangsprojektet/](http://www.sallsyntadiagnoser.se/verksamhet/overgangsprojektet/)**

# Step 1

## Initial letter to the adolescent

Paediatric invites the adolescent to meetings with a transition-coordinator.

## Hi! I want to help you coordinate your healthcare contacts

You are soon to turn 18 which means you will have the right to decide on things by yourself. It also means that you will transfer from Paediatric care to Adult care. To smoothen this transition we want to offer you meetings with a care-coordinator who will help you to map all your healthcare contacts and more if you want to.

### **Why would I need a healthcare coordinator?**

Sometimes the transition from adolescence to adult is hard when it comes to the health care system. Within paediatric care you get a lot support from your parents and the healthcare team but in adult care you will have to take more responsibility. I am sure you will manage it but we want to offer you help with it for a smooth transition.

### **What can a Healthcare coordinator do for me?**

We have developed the role of a healthcare coordinator together with young people with various chronic and rare diseases after their transition from paediatric to adult health care. These young people have used their own experience to create a support system for you to use if, and when, needed.

Me as a healthcare coordinator can support you and give you tips regarding who to call, how to book meetings, ordering new prescriptions or many more things. I can also join you as a support in your meetings with doctors or other authorities.

### **Where can I meet and contact my healthcare coordinator?**

There are various ways to contact me as your healthcare coordinator. We can talk on the phone, via Skype or other chat forums. We will also meet in person and those meetings will take place at your Center of Rare Disease at Karolinska Hospital in Stockholm.

### **So, what's next?**

In about two weeks I'll call you to answer your questions and you can then decide if you're interested in having a personal healthcare coordinator. You don't need to take that decision now and it will be up to you for how long you want to use this service.

However, before our initial contact I would like you to fill out the form attached to this letter and send it back to me. A prepaid envelope is included.

Do not hesitate to contact me if you have any further question. You can contact me via phone, text message or e-mail. .

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Kind regards,  
NN  
Healthcare coordinator  
NN@NN.se  
070xxxxxxx

**SVLLSYNTA  
DIAGNOSER**  
RARE DISEASES SWEDEN

## Send back to healthcare coordinator 1

My name: .....  
My social security number: .....  
My cell phone: .....  
My e-mail: .....

**A few words about me, for you to know before we meet:**

.....  
.....  
.....  
.....

**Do you want me to check your medical journal before our meeting?**

☐ Yes ☐ No

**Things listed below show what I do by myself and what I get help with  
(e.g. parents, legal guardian, assistant):**

**Health care contacts - who is coordinating those today?**

☐ Me ☐ Someone else

**Meetings - booking and organising appointments**

☐ Me ☐ Someone else

**Referrals - getting referrals to relevant doctors**

☐ Me ☐ Someone else

**Medication - prescription and dosage**

☐ Me ☐ Someone else

**Assistive devices - what do I need how to get and how to handle them**

☐ Me ☐ Someone else

**Certificate of need - which do I need and how to get them**

☐ Me ☐ Someone else

**Meetings with doctors and other healthcare staff**

☐ Me ☐ Someone else

## Send back to healthcare coordinator 2

**Other things I do by myself:**

.....  
.....  
.....  
.....

**I would like the healthcare coordinator to help me with the following:**

- ☐ Health Care Contacts – to keep track of who is helping me with what
- ☐ Meetings – book and keep track of
- ☐ Referrals - coordinate and book
- ☐ Medications - keep track of my medications and prescriptions
- ☐ Assistive devices – what kinds are there and how do I get access to them
- ☐ Disability certificates – keep track of which I need and how to get them
- ☐ Join me in different kind of meetings

**Feel free to add more things if required:**

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.....  
.....  
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**Please send back the completed form using the envelope added to this letter (no stamps needed).**

## Step 2

### The first telephone call

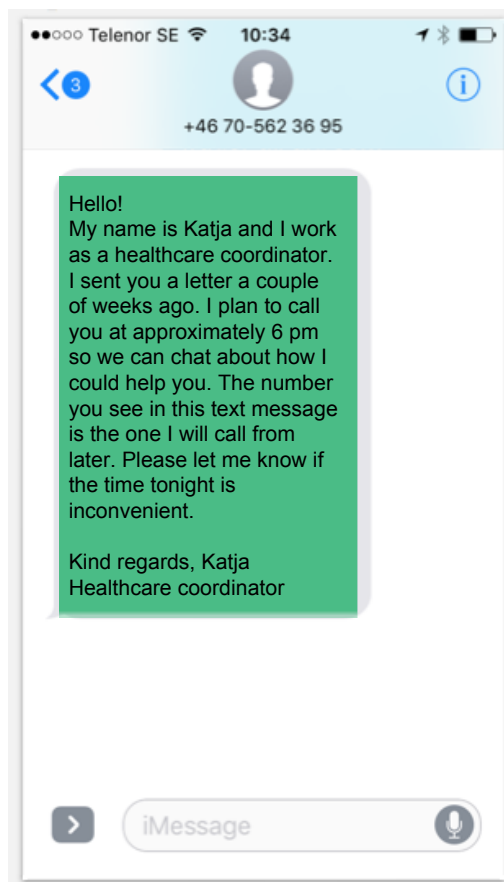
Guide for first phone call with the adolescent.  
Approximately 2 weeks after invitation.

## Healthcare coordinator contacts adolescent

### Step 1:

**Send a text message in preparation for your upcoming phone call.**

- Include who you are, why you're texting and that you will call later. (Suggested text below)
- It's recommended to text from the same number that you will use later since many tend not to answer unknown numbers.



**Turn around**

## Healthcare coordinator contacts adolescent

### Step 2:

**Call the adolescent**

Important areas to cover:

- Short introduction, present yourself
- Ask if he/she has read the letter (if not: inform about the service and ask if you can help with the form)
- If you did get back the form: read and discuss
- Ask if there are any further questions
- Explain about the time frame and the next step
- Make clear that a first meeting is absolutely voluntarily and without any obligations
- Book a meeting (= Meeting 1)
- Ask if there is anybody special that the youth wants to be present at this first meeting (e.g. parent/other doctor etc.)
- Make sure to explain that the adolescent may come alone or bring someone.
- Ask if he/she wants you to read the medical journals before the meeting.
- Make sure to repeat how you can be contacted in case of questions afterwards.

**It is important to create a trustful atmosphere, it can be scary when someone unknown calls.**

- Do not call during school hours, between 4-8 pm is the best.
- Use a professional tone and talk direct to the youth.
- Make sure not to call from a hidden number. Always use the number you texted from initially.
- Call back several times if he or she won't answer the first time.
- Do not use the phrase "patient".

# Step 3

## A healthcare coordinators handbook

Tools for the Healthcare coordinator meeting  
support for communication and documentation

Healthcare coordinator  
Meeting with:



## Meeting 1

### Get to know each other

- What's new since we last met
- Explain how healthcare coordinator can help
- What does the adolescent need help with (Checklist)
- Discussion based on conversation cards (se tips)
- Sum up the meeting (who does what)
- Plan and book next meeting
- Who will join the next meeting
- Adolescent gets his/her own set of conversation cards

### Notes from the meeting

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## Meeting 2

### Plan healthcare coordination

- What's new since we last met
- Discussion based on conversation cards
- Sum up the meeting (who does what)
- Does the adolescent want to continue
- Plan and book the next meeting

### Notes from the meeting

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## Tips: How to use conversation card



Be sure not to take over but let the adolescent choose cards by him/herself. The cards help to decide upon topics, to form and control the discussion and inform the adolescent about which areas in which to expect help and support.



Spread the cards on a table and let the adolescent read them. You may also offer to read out loud what the cards say.



Sometimes it may be better not to use all the cards. You may choose those cards you wish to use during the meeting. If you plan to use many, you may want to set aside the more sensitive cards until the end of the session when you got to know each other better.



When the adolescent has chosen a set of cards for you to discuss, put the rest aside and focus on the chosen ones.



If the adolescent wants to address something not in the cards you can always create new cards. The set includes some blank cards for this purpose.

## The healthcare coordinator's commandments:

- 1 Always meet the adolescent as a person, not as a patient
- 2 Focus should always be on the adolescent
- 3 Create a comfortable and trustful setting when meeting with the adolescent
- 4 Create confidence in the adolescent that you as a Healthcare coordinator will be there for them
- 5 Let things take time, don't rush

My checklist: Who does what?

Date:

Healthcare contacts - overview about who does what

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Meetings – booking and keeping track of the dates

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Referrals – getting referrals to my healthcare contacts

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Medications – who keeps track of my medication and prescriptions

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Assistive devices – what do I need and how do I get access to them

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Certifications - who keeps track of which I need and how to get them

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Appointments with doctors and other medical staff

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Other things I do by myself

My checklist: Who does what?

Date:

Healthcare contacts - overview about who does what

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Meetings – booking and keeping track of the dates

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

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Comment:

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☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Assistive devices – what do I need and how do I get access to them

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Certifications - who keeps track of which I need and how to get them

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Appointments with doctors and other medical staff

☐ My task ☐ Parents/other ☐ Coordinator

Comment:

Other things I do by myself

## Step 4

### Conversation cards

The following cards suggest a broad range of topics the adolescent may pick for discussion with the healthcare coordinator

### Conversation Cards: My healthcare

My health care contacts today	My contacts after healthcare transition
Different roles in the health care system	Shared responsibilities: me, my parents and my healthcare coordinator
When and how I want my healthcare coordinator to join appointments	My legal health care rights
Help with my medicines	My medicines
What personal aids do I have	Help with my personal assistive devices




### Conversation Cards: My healthcare

Help with my prescriptions	Prescriptions – how does it work?
My certificate	Certificates - how do they work
Medical journal - how does it work?	Help with my medical journal
Referrals – how do they work	Help with referrals
Urgent problems	Where to find help if feeling mentally ill




Conversation Cards: My life

Me as a person	My healthcare coordinator as a person
My story and my background	Work and school
Future	Family
Me and my parents	Friends
Body and relations	Sex and relationships



Conversation Cards: My life

Food and nutrients	My mental health
Things worrying me	What it's like to have a rare disease
Thins I struggle with right now	Thins I feel good about right now



Conversation cards: Other instances I'm connected to

Social Security Service	Public Employment Service
Youth counselling center	Dentist
Other contacts	School
Habilitation	Legal guardian
Support and Service for functional impairments	Travel service



Conversation cards: Other instances I'm connected to




# Step 5

## Care map

A tool for better knowledge of ones  
diagnosis and healthcare contacts

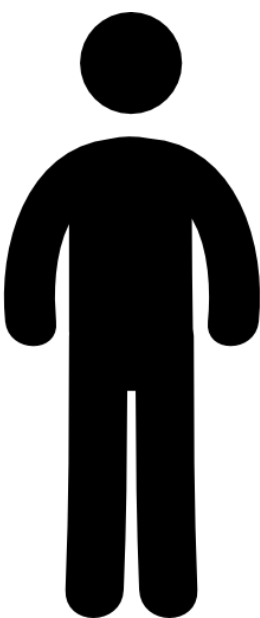
# Care map:

## Material for print



Name:

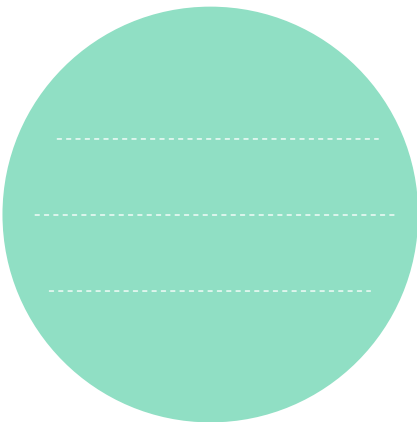
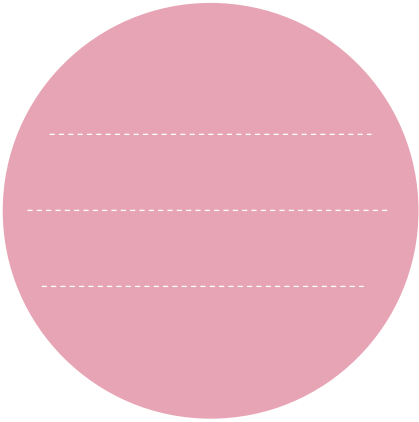
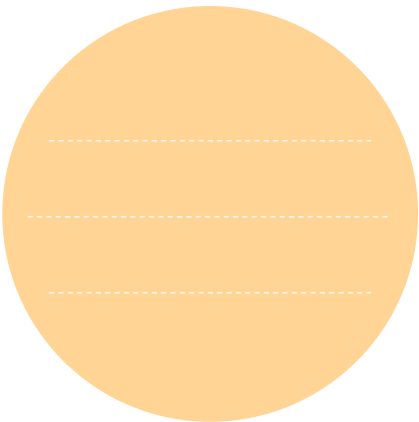
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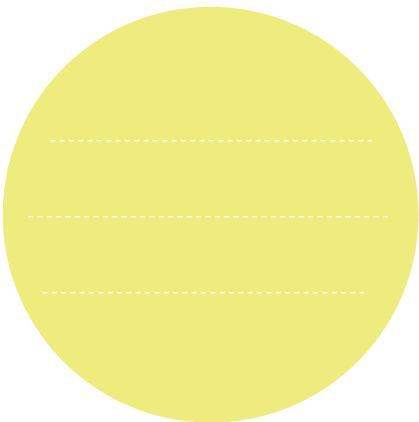
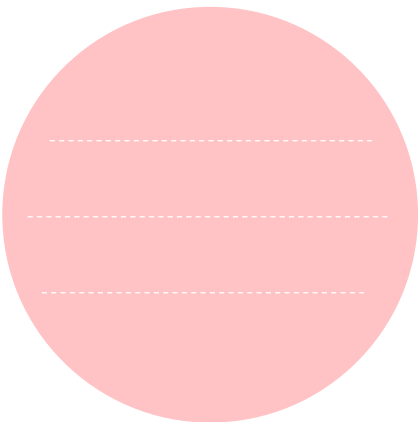
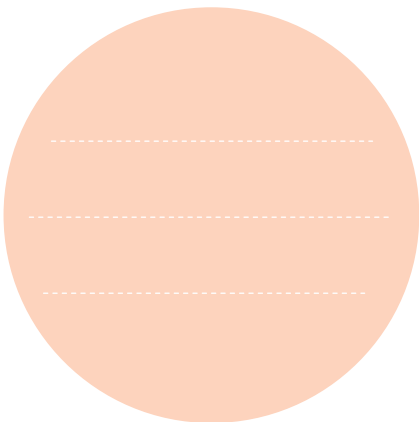
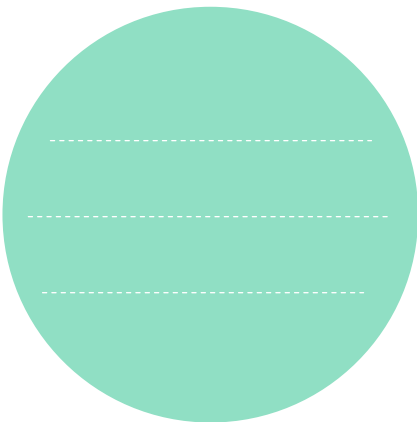
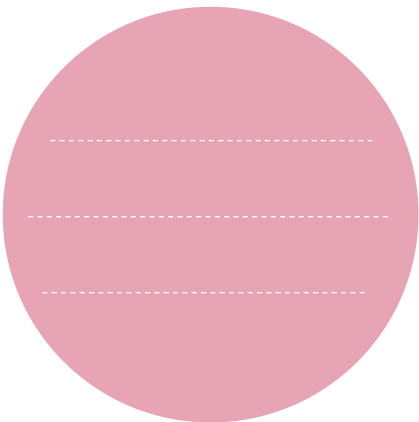
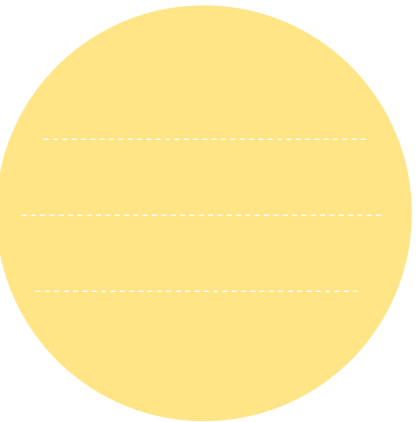
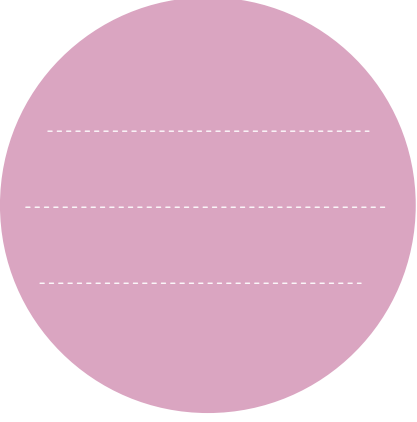
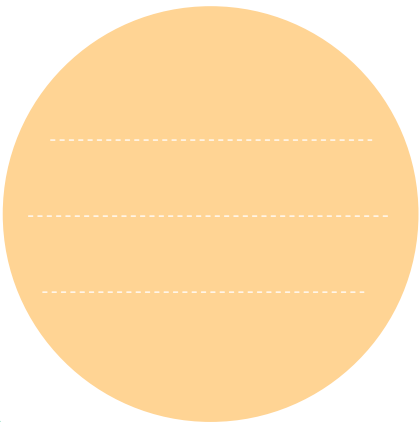
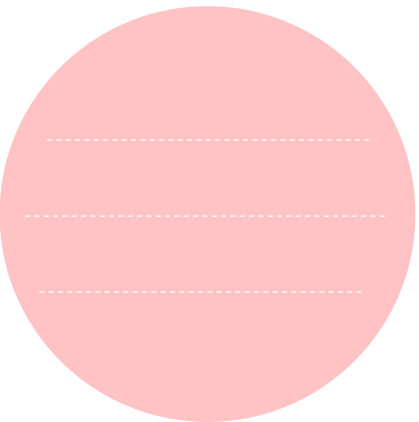
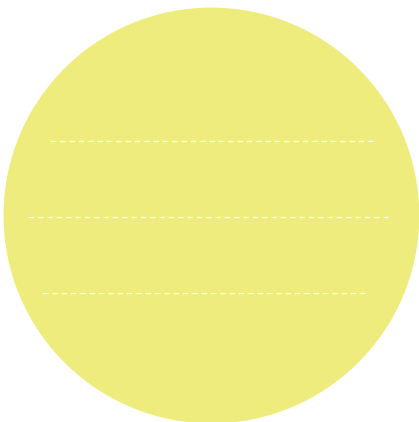
Name:

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1. Cut out circles
2. Write one body part in each circle
3. To be used as arms in the contact map



Where: \_\_\_\_\_

Why: \_\_\_\_\_

What: \_\_\_\_\_

Who: \_\_\_\_\_

How often: \_\_\_\_\_

Where: \_\_\_\_\_

Why: \_\_\_\_\_

What: \_\_\_\_\_

Who: \_\_\_\_\_

How often: \_\_\_\_\_

Where: \_\_\_\_\_

Why: \_\_\_\_\_

What: \_\_\_\_\_

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How often: \_\_\_\_\_

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