

Transition Care Pathway



Paediatrics →

transition maturity 12 ▶

transition maturity 13 ▶

transition maturity 14 ▶

transition maturity 15 ▶

transition maturity 16 ▶

transition maturity 17 ▶

transition maturity 18 ▶

▶ Adult care



This care pathway Transition is a tool for endocrinologists, nurse specialists and patients to determine a patient's transition readiness. The care path is based on the five pillars for transition mentioned in the in-depth quality module on transition care for adolescents and young adults with adrenal cortex insufficiency. The five pillars are shown below. Possible interventions are listed for each year (clickable), to help the patient move forward with the goal of achieving the best possible transition to adult care.



The 5 pillars of transition care



1. Knowledge



2. Self-management



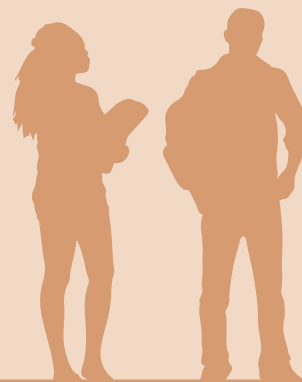
3. Parents/carers



4. Social participation



5. Care organisation



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Disclaimer

This brochure describes the Dutch situation.

The original brochure was designed in the Dutch language and for the Dutch situation. Please bear in mind that the process as described in this brochure/folder will not be applicable for all hospitals in all countries. It has only been translated in order to explain to you what we are doing in the Netherlands. Please check with your own local healthcare colleagues, the professionals, your paediatrician, your endocrinologist, whether and how this process can be adapted - in full or at least in part - for the situation in your country. Maybe then with their help some parts of the text might become applicable in the various situations outside the Netherlands.






Please consult www.adrenals.eu for more info.




You can find an electronic edition that can be downloaded and used locally (to find out which phase of transition has been reached) at <https://adrenals.eu/transition/>








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Transition maturity 12 years			
	Description	Roles and responsibilities	Reference / indicator
	<p>Introduction leaflet <i>Own two feet</i></p> <p>Introduction website AdrenalNET</p> <p>Animated films AdrenalNET</p> <p>Explaining child stress schedule</p> <p>Recognising adrenal crisis symptoms</p>	paediatric endocrinologist/ nurse specialist	<p>▶ On your own two feet - introduction</p> <p>▶ adrenals.eu</p> <p>▶ adrenals.eu/video</p> <p>▶ Stress schedule Children - Youth & adrenals.eu/stress-instructions</p> <p>▶ adrenals.eu/what-is-an-addison-crisis-12</p> <p>KNOWLEDGE</p>
	<p>Questionnaire <i>Getting Ready</i> (12 - 14 year olds)</p> <p>Naming own medication</p> <p>Discuss everyday situations</p> <p>Always carry the European emergency stress card with you</p>	nursing specialist	<p>▶ On their own two feet - ready</p> <p>SELF-MANAGEMENT</p> <p>▶ European emergency stress card</p>
	<p>Parent questionnaire</p> <p>Stress instructions parents and child</p> <p>Coaching conversations parents</p> <p>E-learning modules</p>	nursing specialist	<p>▶ On their own two feet - parents</p> <p>▶ Theme page - Stress instructions</p> <p>▶ Stress instruction card - partner friends (pdf)</p> <p>▶ e-Learning Parents of function of the adrenal glands</p> <p>▶ e-Learning Parents of practical examples</p> <p>PARENTS/CARERS</p>
	<p>Themes to discuss:</p> <p>School trip</p> <p>Staying with friends and family</p> <p>Presentation on adrenal disease at primary school</p>	nursing specialist	SOCIAL PARTICIPATION
	Psychological screening	referral psychology	CARE ORGANISATION



Transition maturity 13 years			
	Description	Roles and responsibilities	Reference / indicator
	<p>Introduction leaflet <i>On Own Legs</i></p> <p>Introduction website AdrenalNET</p> <p>Animated films AdrenalNET</p> <p>Introducing mini-documents</p> <p>Recognising adrenal crisis symptoms</p> <p>Stress instructions child</p>	paediatric endocrinologist/ nurse specialist	<ul style="list-style-type: none"> ▶ On your own two feet - introduction ▶ adrenals.eu ▶ adrenals.eu/video ▶ www.bijniernet.nl/mini-docus ▶ adrenals.eu/what-is-an-addison-crisis-12 ▶ Stress schedule Children - Youth & adrenals.eu/stress-instructions
	<p>Questionnaire <i>Getting Ready</i> (12 - 14-year-olds)</p> <p>Naming own medication</p> <p>Effect of medication</p> <p>Taking own medication</p> <p>Discuss everyday situations</p> <p>E-learning modules</p> <p>Always carry the European emergency stress card with you</p>	nursing specialist	<p>▶ On their own two feet - ready</p> <p style="text-align: right; font-weight: bold; color: #f08080;">SELF-MANAGEMENT</p> <ul style="list-style-type: none"> ▶ e-Learning Adolescents with adrenal cortex insufficiency - practical examples ▶ European emergency stress card
	<p>Parent questionnaire</p> <p>Stress instructions parents and child</p> <p>Coaching conversations parents</p> <p>E-learning modules</p>	nursing specialist	<ul style="list-style-type: none"> ▶ On their own two feet - parents ▶ Theme page Stress instructions ▶ Stress instruction card - partner friends (pdf) ▶ e-Learning Parents of function of the adrenal glands ▶ e-Learning Parents of practical examples <p style="text-align: right; font-weight: bold; color: #f08080;">PARENTS/CARERS</p>

	<p>Themes to discuss:</p> <ul style="list-style-type: none"> School trip Staying with friends and family 	<p>nursing specialist</p>	<p>SOCIAL PARTICIPATION</p>
	<p>No</p>		<p>CARE ORGANISATION</p>

Transition maturity 14 years			
	Description	Roles and responsibilities	Reference / indicator
	<p>Introduction leaflet <i>On Own Legs</i></p> <p>Introduction website AdrenalNET</p> <p>Animated films AdrenalNET</p> <p>Mini-documents</p> <p>Adrenal crisis symptoms recognised</p> <p>Adrenal App</p>	paediatric endocrinologist/ nurse specialist	<p>▶ On your own two feet - introduction</p> <p>▶ adrenals.eu</p> <p>▶ adrenals.eu/video</p> <p>▶ www.bijniernet.nl/mini-docus</p> <p>▶ adrenals.eu/what-is-an-addison-crisis-12</p> <p>▶ adrenals.eu/app</p> <p style="text-align: right;">KNOWLEDGE</p>
	<p>Questionnaire <i>Getting Ready</i> (12 - 14-year-olds)</p> <p>Naming own medication</p> <p>Effect of medication</p> <p>Taking own medication</p> <p>Discuss everyday situations</p> <p>Dealing with stressful situations</p> <p>Dealing with emotions</p> <p>E-learning modules</p> <p>Always carry the European emergency stress card with you</p>	nursing specialist	<p>▶ On their own two feet - ready</p> <p>▶ Information brochure AGS (pdf)</p> <p>▶ www.bijniernet.nl/video/ags-mini-documentaire</p> <p>▶ adrenals.eu/how-an-emergency-injection-works</p> <p>▶ www.bijniernet.nl/video/minidocu-ouders-helpen-ouders-of-a-medium-scholar</p> <p>▶ Stress schedule - children - adolescents</p> <p>▶ e-Learning Adolescents with adrenal cortex insufficiency - practical examples</p> <p>▶ European emergency stress card</p> <p style="text-align: right;">SELF-MANAGEMENT</p>
	<p>Parent questionnaire</p> <p>Stress instructions parents and child</p> <p>Coaching conversations parents</p> <p>E-learning modules</p>	nursing specialist	<p>▶ On their own two feet - parents</p> <p>▶ Theme page –Stress instructions</p> <p>▶ Stress instruction card - partner friends (pdf)</p> <p>▶ e-Learning Parents of function of the adrenal glands</p> <p>▶ e-Learning Parents of practical examples</p> <p style="text-align: right;">PARENTS/CARERS</p>

	<p>Thema's te bespreken</p> <ul style="list-style-type: none"> School trip Staying with friends and family 	<p>nursing specialist</p>	<p>SOCIAL PARTICIPATION</p>
	<p>No</p>		<p>CARE ORGANISATION</p>



Transition maturity 15 years			
	Description	Roles and responsibilities	Reference / indicator
	<p>Introduction leaflet <i>On Own Legs</i></p> <p>Introduction website AdrenalNET</p> <p>Animated films AdrenalNET</p> <p>Mini-documents</p> <p>Recognising adrenal crisis symptoms</p> <p>Stress instructions child and parents</p> <p>Adrenal App</p>	paediatric endocrinologist/ nurse specialist	<p>▶ On your own two feet - introduction</p> <p>▶ adrenals.eu</p> <p>▶ adrenals.eu/video</p> <p>▶ www.bijniernet.nl/mini-docus</p> <p>▶ adrenals.eu/what-is-an-addison-crisis-12</p> <p>▶ Stress schedule - children - adolescents</p> <p>▶ adrenals.eu/app</p> <p style="text-align: right;">KNOWLEDGE</p>
	<p>Questionnaire <i>Steady</i> (14 - 16 jarigen)</p> <p>Naming own medication</p> <p>Effect of medication</p> <p>Taking own medication</p> <p>Discuss everyday situations.</p> <p>Dealing with stressful situations</p> <p>Dealing with emotions</p> <p>E-learning modules</p> <p>Always carry the European emergency stress card with you</p>	nursing specialist	<p>▶ On its own two feet - steady</p> <p>▶ De Medicine roll</p> <p>▶ adrenals.eu/how-an-emergency-injection-works</p> <p>▶ e-Learning Adolescents with adrenal cortex insufficiency - practical examples</p> <p>▶ Information brochure AGS (pdf)</p> <p style="text-align: right;">SELF-MANAGEMENT</p> <p>▶ European emergency stress card</p>
	<p>Parent questionnaire</p> <p>Stress instructions parents and child</p> <p>Coaching conversations parents</p> <p>E-learning modules</p>	nursing specialist	<p>▶ On their own two feet - parents</p> <p>▶ Theme page –Stress instructions</p> <p>▶ Stress instruction card - partner friends (pdf)</p> <p>▶ e-Learning Parents of function of the adrenal glands</p> <p>▶ e-Learning Parents of practical examples</p> <p style="text-align: right;">PARENTS/CARERS</p>





	<p>Themes to discuss:</p> <ul style="list-style-type: none"> School trip Staying with friends and family Effects of alcohol and drugs 	<p>nursing specialist</p>	<p>SOCIAL PARTICIPATION</p> <p>► www.jellinek.nl/informatie-over-alcohol-drugs</p>
	<p>No</p>		<p>CARE ORGANISATION</p>



Transition maturity 16 years

	Description	Roles and responsibilities	Reference / indicator
	<p>Introduction leaflet <i>On Own Legs</i></p> <p>Introduction website AdrenalNET</p> <p>Animated films AdrenalNET</p> <p>Mini-documents</p> <p>Stress schedule adults</p> <p>Recognising adrenal crisis symptoms</p> <p>Knowing long-term complications</p> <p>Stress instructions child and parents</p> <p>Adrenal App</p> <p>Learning to understand laboratory results</p>	paediatric endocrinologist/ nurse specialist	<ul style="list-style-type: none"> ▶ On your own two feet - introduction ▶ adrenals.eu ▶ adrenals.eu/video ▶ www.bijniernet.nl/mini-docus ▶ Stress instructions - adults ▶ adrenals.eu/what-is-an-addison-crisis-12 <p style="text-align: right; font-weight: bold; color: #c0c0c0;">KNOWLEDGE</p>
	<p>On consultation only</p> <p>Go questionnaire (16 - 18 year olds)</p> <p>Get 16-year-olds to sign consent form</p> <p>Naming own medication</p> <p>Effect of medication</p> <p>Taking own medication</p> <p>Discuss everyday situations</p> <p>Dealing with stressful situations</p> <p>Dealing with emotions</p> <p>E-learning modules</p> <p>Always carry the European emergency stress card with you</p>	nursing specialist	<ul style="list-style-type: none"> ▶ On its own two feet - steady ▶ Information brochure AGS (pdf) ▶ www.jadokterneedokter.nl ▶ Theme page –Stress instructions <p style="text-align: right; font-weight: bold; color: #e0e0e0;">SELF-MANAGEMENT</p> <ul style="list-style-type: none"> ▶ adrenals.eu/how-an-emergency-injection-works ▶ e-Learning Adolescents with adrenal cortex insufficiency - practical examples ▶ European emergency stress card

	<p>On consultation only</p> <p>Stress instructions incl syringe instructions</p> <p>Preparation for polio through questionnaires</p> <p>Diary in Adrenal App (only on IOS smart phones)</p>		<p>▶ adrenals.eu/how-an-emergency-injection-works</p> <p>▶ Adrenal App</p> <p>SELF-MANAGEMENT</p>
	<p>Parent questionnaire</p> <p>Stress instructions parents and child</p> <p>Coaching conversations parents</p> <p>E-learning modules</p>	<p>nursing specialist</p>	<p>▶ On their own two feet - parents</p> <p>▶ Theme page –Stress instructions</p> <p>▶ Stress instruction card - partner friends (pdf)</p> <p>PARENTS/CARERS</p>
	<p>Themes to discuss:</p> <p>School trip</p> <p>Staying with friends and family</p> <p>Effects of alcohol and drugs</p> <p>Going out</p> <p>Relationship/sexuality</p>	<p>nursing specialist</p>	<p>▶ Information brochure AGS (pdf)</p> <p>▶ www.jellinek.nl/informatie-over-alcohol-drugs</p> <p>▶ www.seksualiteit.nl/seks-jouw-leven/relaties/een-relatie</p> <p>SOCIAL PARTICIPATION</p>
	<p>Joint consultation with nursing specialist</p> <p>Psychological screening</p> <p>Patient portal or other electronic provision of information</p>	<p>nursing specialist en nursing specialist interne Referral psychology</p>	<p>CARE ORGANISATION</p>

Transition maturity 17 years			
	Description	Roles and responsibilities	Reference / indicator
	<p>Introduction leaflet op <i>On Own Legs</i></p> <p>Introduction website AdrenalNET</p> <p>Animated films AdrenalNET</p> <p>Mini-documents</p> <p>Stress schedule adults</p> <p>Recognising adrenal crisis symptoms</p> <p>Knowing long-term complications</p> <p>Stress instructions child and parents</p> <p>Adrenal App</p> <p>Learning to understand laboratory results</p>	paediatric endocrinologist/ nurse specialist	<p>▶ Introductie ready - steady - go</p> <p>▶ adrenals.eu</p> <p>▶ adrenals.eu/video</p> <p>▶ www.bijniernet.nl/mini-docus</p> <p>▶ adrenals.eu/what-is-an-addison-crisis-12</p> <p>▶ Stress instructions adults</p> <p style="text-align: right; font-weight: bold;">KNOWLEDGE</p> <p>▶ Theme page –Stress instructions</p> <p>▶ adrenals.eu/app</p> <p>▶ Laboratory results</p>
	<p>On consultation only</p> <p>Go questionnaire (16 - 18 year olds)</p> <p>Get 16-year-olds to sign consent form</p> <p>Naming own medication</p> <p>Effect of medication</p> <p>Taking own medication</p> <p>Discuss everyday situations</p> <p>Dealing with stressful situations</p> <p>Dealing with emotions</p> <p>On consultation only</p> <p>E-learning modules</p>	nursing specialist	<p>▶ On your own two feet - Go</p> <p>▶ Information brochure AGS (pdf)</p> <p>▶ Medicine roll</p> <p style="text-align: right; font-weight: bold;">SELF-MANAGEMENT</p> <p>▶ adrenals.eu/how-an-emergency-injection-works</p> <p>▶ e-Learning Adolescents with adrenal cortex insufficiency - practical examples</p>

	<p>Stress instructions incl syringe instructions</p> <p>Preparation for polio through questionnaires</p> <p>Diary in Adrenal App (only on IOS smartphone)</p> <p>Always carry the European emergency stress card with you</p>		<p>SELF-MANAGEMENT</p> <ul style="list-style-type: none"> ▶ Adrenal App ▶ European emergency stress card
	<p>Parent questionnaire</p> <p>Stress instructions friends partner</p> <p>E-learning modules friends partner</p>	<p>nursing specialist</p>	<p>PARENTS/CARERS</p> <ul style="list-style-type: none"> ▶ On their own two feet - parents ▶ Stress instruction card - partner friends (pdf)
	<p>Themes to discuss:</p> <p>School trip</p> <p>Staying with friends and family</p> <p>Effects of alcohol and drugs</p> <p>Going out</p> <p>Relationship/sexuality</p> <p>Travel</p> <p>Career choice, study</p>	<p>nursing specialist</p>	<p>SOCIAL PARTICIPATION</p> <ul style="list-style-type: none"> ▶ Information brochure AGS (pdf) ▶ www.jellinek.nl/informatie-over-alcohol-drugs ▶ www.seksualiteit.nl/seks-jouw-leven/relaties/een-relatie ▶ www.bijniernet.nl/Travel-vakantie-themapagina ▶ www.patientenfederatie.nl/over-de-zorg/werken-met-chronische-ziekte
	<p>Joint consultation with nursing specialist</p> <p>Patient portal or other electronic provision of information</p>	<p>nursing specialist en nursing specialist interne Referral psychology</p>	<p>CARE ORGANISATION</p>

Transition maturity 18 years			
	Description	Roles and responsibilities	Reference / indicator
	<p>Introduction website AdrenalNET</p> <p>Animated films AdrenalNET</p> <p>Mini-documents</p> <p>Stress schedule adults</p> <p>Recognising adrenal crisis symptoms</p> <p>Knowing long-term complications</p> <p>Stressinstructies</p> <p>Adrenal App</p> <p>Learning to understand laboratory results</p>	<p>Criteria voor transfer</p> <ul style="list-style-type: none"> • Knowledge about the clinical picture • Sufficient selfmanagement and selfreliance • Own responsibility for medication and outpatient visits • Being able to make decisions independently 	<ul style="list-style-type: none"> ▶ Introductie ready - steady - go ▶ adrenals.eu ▶ adrenals.eu/video ▶ www.bijniernet.nl/mini-docus ▶ adrenals.eu/what-is-an-addison-crisis-12 <p style="text-align: right;">KNOWLEDGE</p> <ul style="list-style-type: none"> ▶ Stress instructions adults ▶ adrenals.eu/app ▶ Laboratory results
	<p>On consultation only</p> <p>Questionnaire <i>Hello</i> (18-25 jaar)</p> <p>Get 16-year-olds to sign consent form</p> <p>Naming own medication</p> <p>Effect of medication</p> <p>Taking own medication</p> <p>Discuss everyday situations</p> <p>Dealing with stressful situations</p> <p>Dealing with emotions</p> <p>On consultation only</p> <p>Stress instructions including syringe instructions</p> <p>Preparation for polio through questionnaires</p> <p>E-learning modules</p> <p>Always carry the European emergency stress card with you</p>	<p>nursing specialist</p>	<ul style="list-style-type: none"> ▶ On your own two feet -Hello <p style="text-align: right;">SELF-MANAGEMENT</p> <ul style="list-style-type: none"> ▶ Theme page –Stress instructions ▶ Medicine roll ▶ adrenals.eu/how-an-emergency-injection-works ▶ e-Learning Adolescents with adrenal cortex insufficiency - practical examples ▶ European emergency stress card

	<p>Diary in Adrenal App (only on IOS smartphone)</p> <p>Buddy</p> <p>Ning adult care in shared care</p>		<p>► Adrenal App</p> <p>SELF-MANAGEMENT</p>
	<p>Parent questionnaire</p> <p>Who is a carer?</p> <p>Stress instructions friends partner</p> <p>E-learning modules vrienden partner</p>	<p>nursing specialist</p>	<p>► On their own two feet - parents</p> <p>PARENTS/CARERS</p> <p>► Stress instruction card - partner friends (pdf)</p>
	<p>Themes to discuss:</p> <p>School trip</p> <p>Staying with friends and family</p> <p>Effects of alcohol and drugs</p> <p>Going out</p> <p>Relationship/sexuality</p> <p>Travel</p> <p>Career choice, study</p> <p>In rooms</p>	<p>nursing specialist</p>	<p>► Information brochure AGS (pdf)</p> <p>► Mini-docu over AGS bij volwassenen</p> <p>SOCIAL PARTICIPATION</p> <p>► www.jellinek.nl/informatie-over-alcohol-drugs</p> <p>► www.seksualiteit.nl/seks-jouw-leven/relaties/een-relatie</p> <p>► www.bijniernet.nl/Travel-vakantie-themapagina</p> <p>► www.patientenfederatie.nl/over-de-zorg/werken-met-chronische-ziekte</p>
	<p>Joint consultation with nursing specialist</p> <p>Discuss in paediatric endocrinology - endocrinology adults - multidisciplinary consultation</p> <p>Written transfer to internist-endocrinologist</p> <p>Organising informal care</p> <p>Criteria for transfer to internist-endocrinologist check</p> <p>Patient portal or other electronic provision of information</p>	<p>nursing specialist en nursing specialist interne Referral psychology</p>	<p>CARE ORGANISATION</p>

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