



# An Integrated Best Practice Service Model for Cystic Fibrosis in SA

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Government  
of South Australia

SA Health



# 1.0 Background

## 1.1 Cystic Fibrosis Defined

Cystic fibrosis is a genetically inherited disorder, usually diagnosed via newborn screening. In South Australia, on average, 7 babies are diagnosed with CF every year (1 in 2800 live births). However, the numbers of babies diagnosed with CF in any one year has ranged from 1 to 15 over recent years. About 1 in 25 people are asymptomatic carriers of a CF gene mutation (CF Standards, Australia, 2008).

Cystic Fibrosis is a complex multi-system disease commonly evidenced by sinus disease, lung disease, pancreatic insufficiency, gastro-intestinal blockage, fat soluble vitamin deficiency and absence of the vas deferens causing infertility in males. Complications include CF related diabetes, bone disease (arthritis and osteoporosis), female urinary incontinence, renal complications, allergic reactions, drug toxicity, depression/anxiety and compromised venous access. While the manifestation of complications can appear at any age they generally increase in prevalence and severity with increasing age.

There are a number of important strategies which can maintain health and delay the onset of complications and are recommended for all people living with cystic fibrosis. These include daily lung clearance exercises, physiotherapy and nutrition management. For most individuals this is a demanding and time consuming regime and disease burden at an individual level is a significant issue. Various studies have found an average of between 30 and 70% compliance rate across all recommended therapies in children and adults (Llorente et al, 2008).

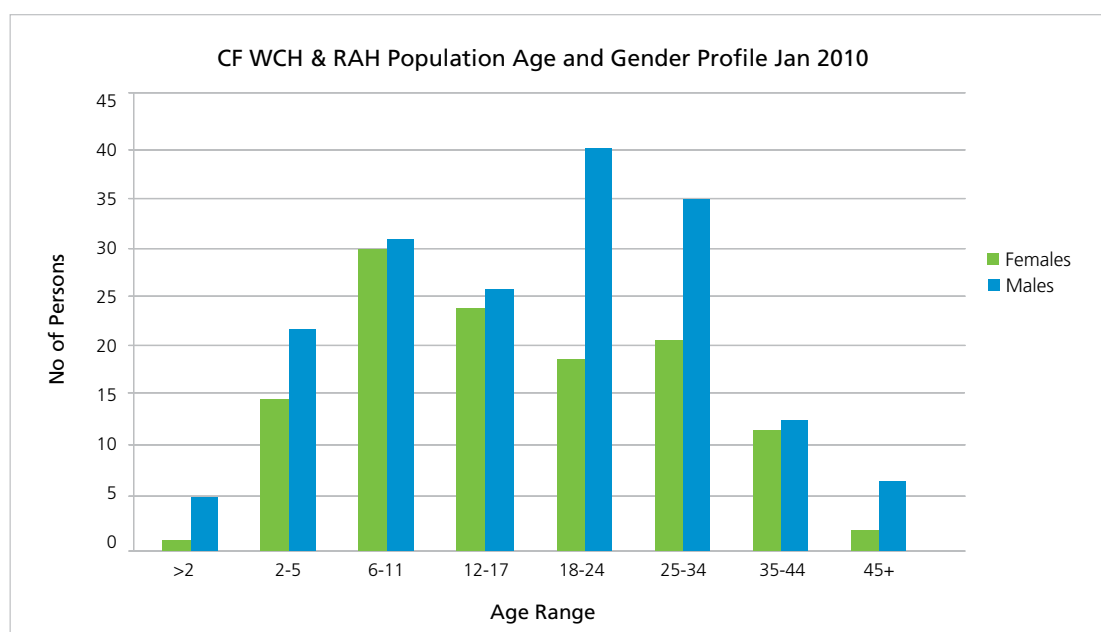
Through improvements in disease management, including specialist CF clinical care, antibiotic therapies, improved airway clearance techniques, nutrition management and pancreatic enzyme replacement therapy, significant advances in survival have been realized. Though comparable Australian data is not available, US data indicates a current median survival of 37 years which is expected to increase to 50 years within the next decade (CF Standards Australia, 2008) as management and therapies are continuously improved over the lifespan.

## 1.2 An overview of CF in SA

In January 2010 there were 303 people with cystic fibrosis who were registered with the Women's and Children's Hospital (WCH) or the Royal Adelaide Hospital (RAH) for ongoing care and management. Ages ranged from under one year old to 57 years old; 49% (N=149) were aged 18 years and older. There were 179 males (59%) compared with 124 females (41%). 24.5% of people with CF registered with the WCH lived in regional SA with 4.5% living interstate, compared with 19.4% of RAH CF patients living in regional SA and 2.3% interstate.

Eighteen people have had a double lung transplant, representing a 64% survival rate of all people who have had a lung transplant since 1990. The current average length of survival post transplant is 5.5 years.

Cystic fibrosis, as a genetically inherited disorder is a 'family' concern. In South Australia, twenty five adults with cystic fibrosis are parents. In addition, nineteen people with CF also have a sibling with CF. Three families have 3 children with CF.



# 1.0 Background

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As at the end of July 2010 there were 160 people with CF (infants, children and young adults) registered as patients of the WCH. Analysis of age range cohorts shows that in the years to 2026-28 there will be between 11 and 24 people transferring to adult services within any one to two year timeframe.

The CF population comprises people with milder forms of the disease who are in relatively good health, people whose health is generally stable, people who are experiencing significant deterioration in health and those with end stage disease, requiring either a lung transplant or comprehensive palliative care.

## 1.3 Development of the Model

Improvements in the management of cystic fibrosis and the associated co-morbidities in recent decades have dramatically changed the expectations and life journey for people living with cystic fibrosis and their families. Care for people with cystic fibrosis and their families must now be cognisant of whole of life issues across an increasing life-span. Services are required to address complexities faced by people with cystic fibrosis and their families both in terms of medical needs and more broadly in recognising and addressing psychosocial needs across the lifespan. As such, the promotion of wellness, self management<sup>1</sup> and a person-centred approach must be key components of cystic fibrosis services in responding to consumer needs and aspirations.

It is within this changing experience of cystic fibrosis that work to review current approaches to CF in SA and the development of a revised integrated model of care has been undertaken. This work has involved close consultation and collaboration with people with cystic fibrosis and clinicians working within the specialised area. The model developed and described below is consistent with The Cystic Fibrosis Standards of Care, Australia (2008), in line with best practice and informed by clinical expertise from CF clinicians and people with CF (including Cystic Fibrosis South Australia).

The model represents a significant shift in the provision of cystic fibrosis care in South Australia. The aim is for the model to be fully established by 2014.

1 "learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition" through programmes "aimed at helping the patient become an active...partner with health care providers" Lorig 1993, p 11

## 2.0 Overview of the Integrated Model

The model emphasises the integration of services across care types and service locations, equity of access to services for all ages and the skilled management of transitions across the lifespan. Where appropriate, there will be a shift in emphasis from hospital-based service to a comprehensive service which includes the delivery of specialist services in community settings and in people's homes, as well as the active promotion of wellness. Specialist cystic fibrosis teams will develop close working relationships with clinicians in regional areas, establishing shared care arrangements where appropriate, and with community support services to support people with cystic fibrosis (and their families) in their communities.

The model is patient-centred, with the active involvement of people with CF in decisions that impact their health and wellbeing being central to planning care. This will include the development of individualised, developmentally appropriate self-management programs, the promotion of wellness and timely access to consumer education and information about the services and options available across developmental life stages and disease progression. Cystic Fibrosis South Australia (CFSA) will have a key role to play in supporting people affected by cystic fibrosis in relation to education and support across these developmental life stages and in encouraging a positive and hopeful perspective.

In addition, the model has a strong life course approach, with the service responses and engagement approaches maturing as the person with CF grows and matures. This will require the development of a planned and structured approach to transition and a team culture enabling the therapeutic relationship to change over time, preparing the young person and their family for this important developmental shift and including a strong self management program.

Specifically, over time the integrated service model requires the following specialist service responses:

- > Identification of a key single point of contact (from within specialist CF team) for each person with CF registered with either the paediatric or adult CF specialist teams. This person is responsible for the development and review of individualised care plans, coordination of care across all settings and advocacy for the patient where required
- > Capacity to respond outside of working hours according to an agreed mechanism.
- > Rapid assessment and intensive multi-disciplinary care at home
- > Ongoing review and management of patients through ambulatory clinics
- > Treatment of acute exacerbations and complications through inpatient admissions or hospital in the home, as determined in partnership with CF specialist staff and the person with CF and their family.

## 3.0 Essential Components of the Model

The model is patient-centred and will facilitate the active involvement of people with CF in planning their care and in participating in those decisions which affect their health. This will be supported by patient charters for both the paediatric and adult specialist team services which outline what consumers can expect from the service and what they can contribute to their care (see attachment 1).

The following service components will be provided from birth, through adolescence and into adulthood across ambulatory care and inpatient care settings by the specialist cystic fibrosis (CF) teams (paediatric and adult).

### 3.1 Across team clinical governance

The model will be supported by an agreed approach to clinical governance across the paediatric and adult CF specialist teams. This will ensure compatible clinical practices and drive the development of collaborative and collegiate approaches across the paediatric and adult specialist teams. This will include a process to review evidence, develop a consensus around best practice in the absence of adequate evidence and oversee the transition pathway and processes. Where there are agreed differences in clinical practice across the teams due to the physiological differences between children and adults, or professional/clinical preference (with no evidence demonstrating a single gold standard practice in the area) then a commitment from both teams to explain those differences to people with CF and their families will be made. This will be supported by clearly established communication processes, shared records, and a self management program which is informed by and supportive of all service components.

### 3.2 Life course approach

In this life-course approach CF services are provided across three key life phases childhood, adolescence and adulthood and as such adolescence is the bridge between childhood and adult services which operate according to very different paradigms. The 'gap' between these paradigms will be, in part, addressed through well planned transition and a deliberate focus on developing a 'bridge' across the paediatric and adult settings which is flexible in responding to the needs of adolescents and young adults. In this way an adolescent specific approach to service delivery will be developed with the support of experts in adolescent health.

The strong connection which can develop between professional and consumer (and their family) as a consequence of being involved with a family over a long period of time, including through times of crisis, must be managed in order that the professional, therapeutic relationship is maintained. This ensures the relationship changes over time to accommodate emerging needs as the child with CF becomes an adolescent and adult. This will require workplace support and debriefing opportunities for clinicians through workplace counselling services and an ongoing, structured approach to professional development and support. In particular, the specialist CF team may seek professional support from experts in working with young people through the developmental issues of adolescence.

#### **Transition to adult services**

"Transition is the planned move of children and young people from paediatric to youth and adult health services, maximising function and potential through the provision of high quality, developmentally appropriate services that continue uninterrupted through adolescence to adulthood." (as developed by the Paediatric Service Plan Workgroup 2010)

Across the specialist CF teams (paediatric and adult) implementation of the agreed SA Transition Principles (see appendix 1) will support the approach to transition. In particular this will include:

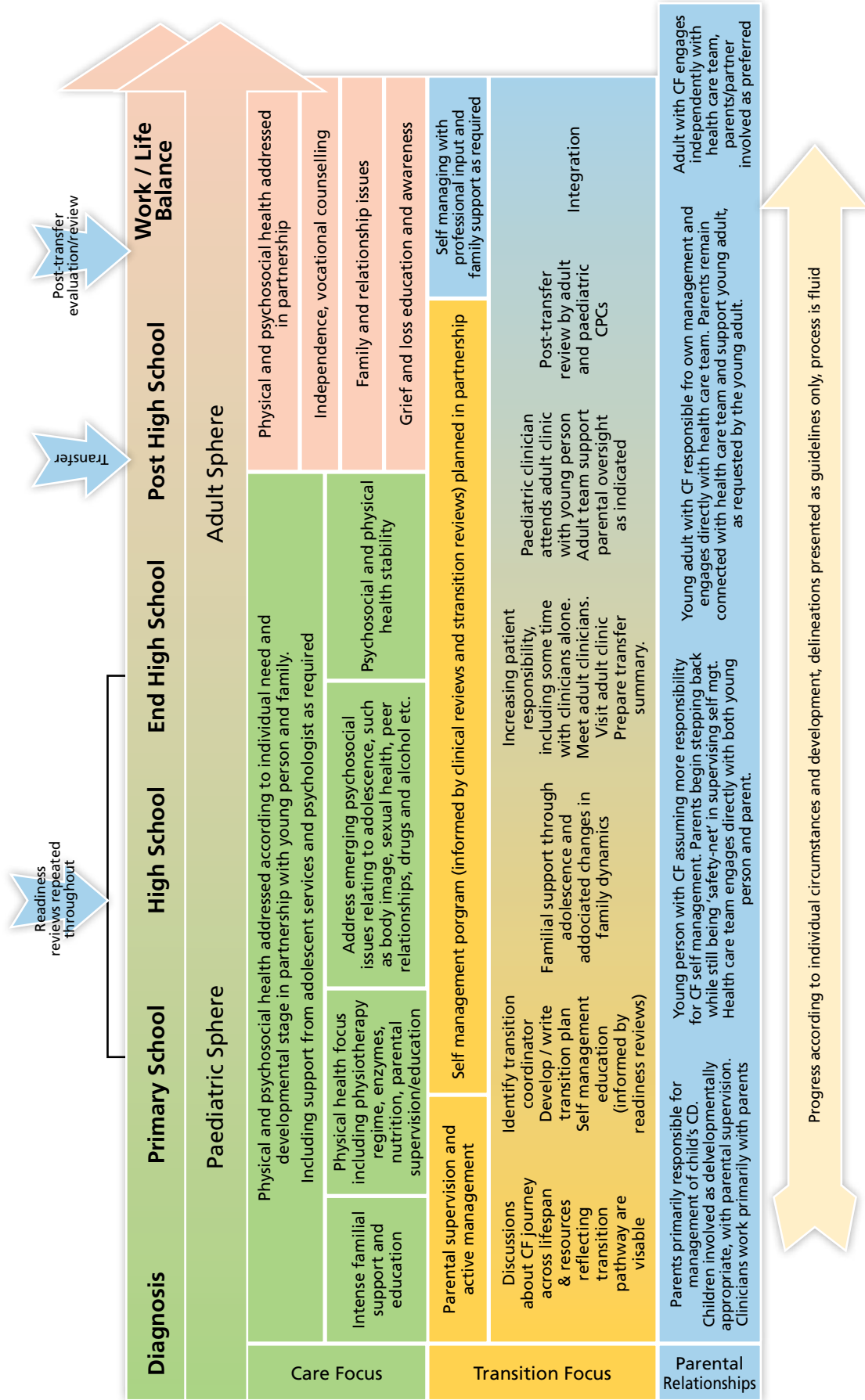
- > the early and ongoing discussion of transition as part of the care journey for an individual with cystic fibrosis,
- > the allocation of a transition coordinator for each cystic fibrosis consumer (CPC in most cases, or other team member with whom the young person has a good rapport)
- > active planning, including a documented transition plan, (developed in conjunction with the individual, their family and both paediatric and adult care teams) that is reviewed and updated regularly and shared across the service.
- > undertaking regular 'readiness' assessments in preparation for transfer and to inform the individual's self management education program,
- > close, ongoing communication between the adult and paediatric care teams,
- > clinic 'cross-over' visits to facilitate familiarity with staff from the adult care team, and
- > 'meet and greet' opportunities with the adult care team (including visiting the adult outpatient clinic and inpatient ward)

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The pathway shown in figure 1 (see following page) depicts a process which begins early and is described in phases broadly aligned with school milestones. Transition is introduced early in the child's care and is a familiar concept for both the child and their family. The phases are aligned with school milestones as guidelines for shifts in approaches to care and additional or changing care requirements, as well as implementation of specific transition activities (e.g. meeting adult care team clinicians). However, these are guidelines only and clinicians will be guided by an individual's development and circumstances.

# 3.0 Essential Components of the Model

Figure 1 – Transition Pathway: From Paediatric to Adult Services





### 3.3 Ambulatory Care

Multi-disciplinary ambulatory care includes the co-ordination, review and provision of ongoing specialist medical, nursing and allied health services to people living with cystic fibrosis and their families. Specifically, it includes services to address physical and psychosocial issues in responding to acute exacerbations and the ongoing management of the condition, including promotion of wellness. These services will be provided by the specialist CF team in out-of-hospital settings such as out-patient clinics, GP Plus Centres, in people's homes, and potentially in country general hospitals (via visiting outreach clinics).

#### **Specialist service central reviews**

Annual reviews will be undertaken with appropriate tests including assessment of current status and progress against the agreed care plan, with a summary report provided to the general practitioner and person with CF. Further, routine scheduled reviews will be undertaken as outlined in the Cystic Fibrosis Standards of Care Australia (2008) according to an individual's specific health status. This will include the development of a single care plan for each individual and transition plan when appropriate (with active involvement of the person with CF and their family). Care plans will include consideration of whole of life issues (such as sexual health and fertility) and the promotion of wellness supported through the self management program and patient preferences in relation to provision of care. Some review clinics may be carried out as outreach clinics as described below.

#### **Outreach clinics by specialist CF team**

Where the number of people with cystic fibrosis within a geographic area is sufficient, the specialist service will investigate the provision of some clinics through local GP Plus Centres and country general hospitals with necessary equipment.

#### **Home-based therapy**

Ambulatory support services will be available to support the provision of care in a person's home. This could include allied health and nursing services such as intensive physiotherapy during periods of 'Hospital In The Home' intra-venous antibiotics. This support will be provided directly by the specialist team or by the local health services supported by the specialist team for people living in rural areas (where shared care arrangements have been established). During periods of home-based therapy there will be support, reviews and proactive contact from the specialist CF team as clinically indicated.

#### **Rapid assessment**

The delivery of an out of hours 'rapid assessment' service by the CF Specialist Team will be developed over time and undertaken according to an agreed process to be determined by the Specialist CF Teams. Care Coordinators will provide information to people with CF and their families as to how, and when to access this service. Clinicians providing the out of hours 'rapid assessment' service will have specialist skills in the management of CF.

The rapid assessment service capability may include:

- > 24 hour clinical support to people with CF and their families
- > Advocacy with other health care teams, e.g. Emergency Department
- > Facilitation of the next step in care (e.g. communicate with emergency department where indicated, arrange urgent outpatient appointment with appropriate specialty)

Potential outcomes from the rapid assessment process include:

- > Further physical assessment of an individual's condition (through multiple, flexible delivery methods including utilisation of videoconferencing technologies for rural and remote residents and partnership arrangements with local generalist clinicians)
- > Increase or change to nature of ambulatory support provided in the home (e.g. increase to daily physiotherapy support for short term)
- > Urgent review within scheduled CF specialist clinics (with reserved appointments being available for this purpose) where available in suitable timeframe
- > Referral to other specialty area such as endocrinology.

People living in the country will have access to rapid assessment through the development of relationships between local health service staff and the specialist CF team (see page 12) supported by technologies to facilitate remote consultations (such as videoconferencing, video phone).

## 3.0 Essential Components of the Model

Further detail regarding the clinical scope of the rapid assessment service will be required and translation of this into information for people affected by cystic fibrosis will be vital in ensuring effective utilisation.

There is potential for the rapid assessment mechanism to be used for facilitating immediate communication with the team by GPs and shared care partners when urgent advice or consultations are required. Guidelines to support this will be developed over time within the shared care arrangements to ensure effective use of this service option.

### Supportive care

The specialist CF teams will address the broader needs of consumers and their families through the provision of social work and psychology services and through links with other support services such as DECD Child Health and Education Support Services (CHESS), carer respite services, vocational support agencies and other non-government organisations providing supportive care.

Key workers will make proactive contact with people with cystic fibrosis who indicate a desire for this in order to 'touch base' and monitor clinical and/or psychosocial issues depending on individual circumstances.

Supporting the person with cystic fibrosis and their families through periods of change such as the first hospitalisation and transition from paediatric to adult services will be important components of care.

Cystic Fibrosis SA will continue to provide support and advocacy for people with cystic fibrosis and their families affected by cystic fibrosis. Including, peer support mechanisms (possibly online), linkages to other support mechanisms and direct service provision and support as per their current service profile (counselling, education and information, newly diagnosed support, equipment, sibling and parent support, transplant support, etc).

Additional Considerations:

*Further investigation into possible mechanisms for peer support which do not pose a cross-infection risk will be required as a component of supportive care.*

### 3.4 Inpatient care

People with cystic fibrosis may require hospital admission for care relating specifically to their CF, or for non-cystic fibrosis related illness or injury; some of these non-CF related admissions may be made to private hospitals.

For those admissions relating to cystic fibrosis and its various complications, the person with cystic fibrosis will have their care coordinated by staff from the specialist CF team working closely with the hospital and ward staff. The team will oversee planned and unplanned admissions; reviewing, stabilising and setting treatment plans for the course of the admission. Allied health and support services would be provided during admission by the specialist team.

Discharge from an acute admission relating to cystic fibrosis will trigger the review of the person's care plan and alterations will be made accordingly. The specialist team will arrange for any required changes to the provision of ambulatory care services, including home based therapy and scheduling of specialist clinic reviews as part of the post-discharge support. A discharge summary and any care plan alterations will be communicated to those involved in the individual's care including GP, key staff within the team, and other specialists as indicated. Discharge time will be discussed with the person with CF, and the necessary support services coordinated (including pharmacy) to ensure a smooth and efficient process.

When a person with cystic fibrosis is admitted to hospital for a non-cystic fibrosis related illness or injury the specialist CF team will act as a consultant service to the treating team as required. Further exploration of the issues relating to the public/private interface in these circumstances will be required.

### 3.5 Referral pathways and key service linkages

The care of a person with cystic fibrosis will often involve specialties outside the specialist CF team, such as palliative care, endocrinology, and psychiatry. In order for multiple specialist involvement to occur in an integrated approach agreed communication and shared decision making processes will be required.

#### **Lung transplant team**

Following a decline in lung function for a person with cystic fibrosis, the cystic fibrosis team refers to the lung transplant team. At this point the lung transplant team will undertake to assess an individual for transplant suitability, while the specialist CF team remains the lead care team. Lung transplants for SA residents are undertaken primarily in Victoria with pre and post care provided by the lung transplant team based at the RAH. Following the lung transplant and the associated rehabilitation undertaken interstate the person returns to SA and is managed by the lung transplant team.

#### **Post transplant**

The lung transplant team will have a direct link and agreed communication processes with the specialist CF teams and be included in case management processes.

#### **End of life care**

Contact with palliative care services will be offered early to people with CF and their families as part of the milieu of services prior to person reaching 'end of life care'. The person with CF and their families will have the opportunity to establish a sense of what this service offers, have thought about and possibly discussed some of the related issues and have an established relationship with palliative care staff.

Over time, and as appropriate for each individual and their family, the involvement with palliative care staff may increase from some palliation of specific symptoms while still primarily managed by the specialist CF team to being primarily managed by the palliative care staff at end of life. In this way the involvement of palliative care and end of life care does not necessarily occur at a single point in time but rather may be managed as a gradual transition according to individual need and circumstances.

This early engagement with palliative care services will be by individual choice. In other circumstances, referral to palliative care services will be made in consultation with the person with CF and their family when appropriate.

#### **Collaboration with community based services**

People with cystic fibrosis will be encouraged to make the choice to develop a long term relationship with a single (or small number of) GP(s) (Cystic Fibrosis Standards of Care 2008). Over time the GP is able to learn about the person's condition with support from the specialist CF team, and thus become an important part of the support network available to the person with CF and their family. Furthermore, good communication between the cystic fibrosis service and the GP is essential in optimising care<sup>2</sup>. General practitioners involved in providing care to people with cystic fibrosis will have access to advice from the specialist CF team (via an agreed process with the relevant Care Coordinator). Ongoing GP care does not replace specialist CF coordination and service provision, rather supports and complements it at the local, community level.

This collaborative and supportive approach will be extended to the service's work with local generalist health care providers other agencies involved in supporting the person and their family.

#### **Shared care**

People living with cystic fibrosis in country South Australia (currently approximately 23% of registered cystic fibrosis patients) face some particular challenges in accessing specialist cystic fibrosis services. As such, specialist CF teams will encourage rural and remote residents to develop a 'shared care' approach to their care in which the specialist service will work in partnership with a local paediatrician or general physician (or GP where these are not available locally) and local health service in providing ongoing care in line with an agreed care plan. The local medical practitioner will have access to the specialist cystic fibrosis service (via an agreed communication process) for professional support and guidance as required. This approach will relieve some of the requirements for travel to Adelaide.

2 pg 36, standard 4.2.9a of the Cystic Fibrosis Standards of Care 2008

## 3.0 Essential Components of the Model

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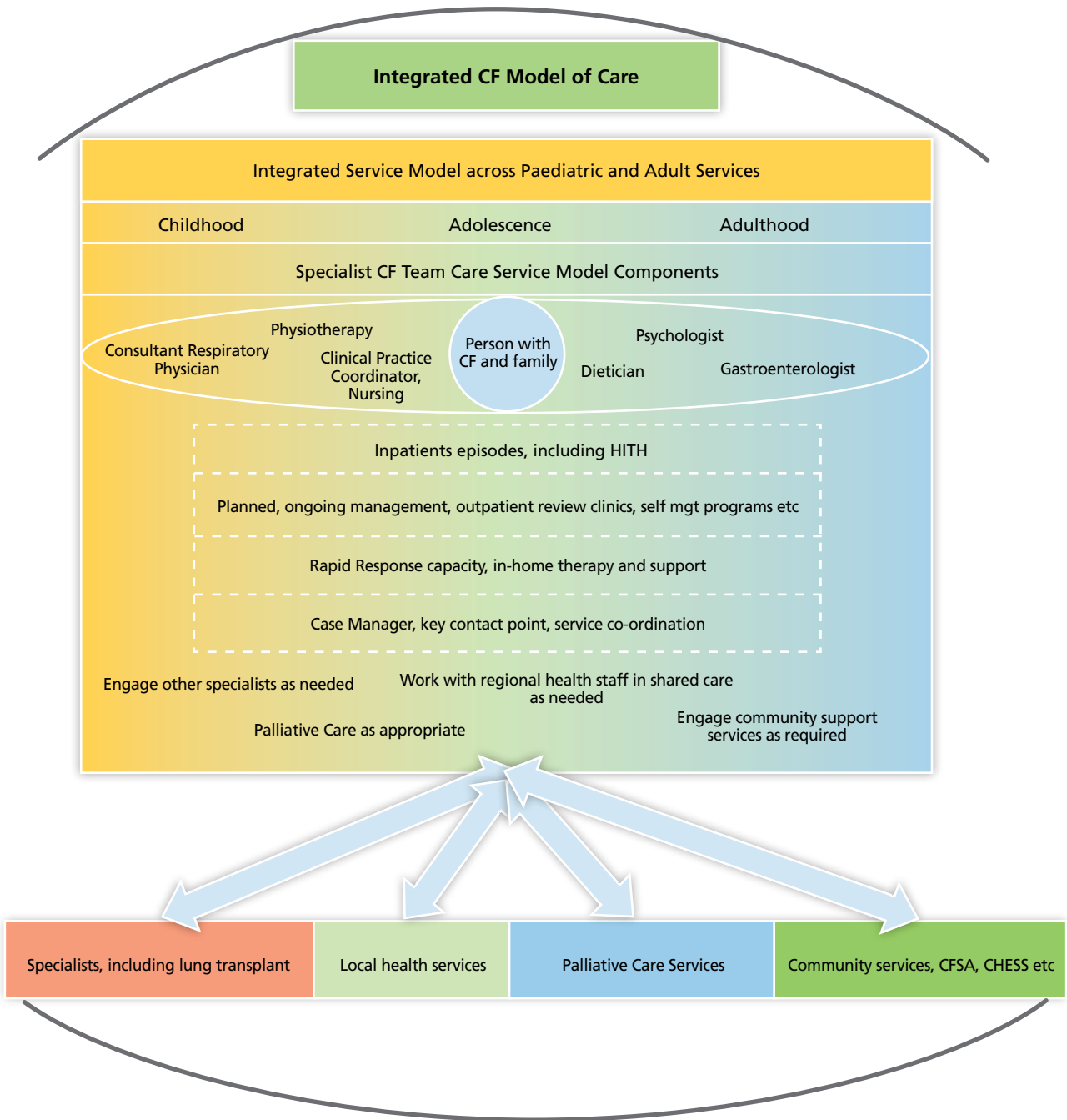
This 'shared care' will be further extended to nursing and allied health where, supported by specialist cystic fibrosis clinicians, they will provide elements of the person's care as determined by the care plan and partnership arrangements. This partnership arrangement will be supported by regular outreach clinics in specific rural locations (this will require further consultation and investigation). These clinics will provide specialist reviews for people with cystic fibrosis and provide professional development opportunities for local clinicians (medical, nursing and allied health) involved in the provision of cystic fibrosis related services.

Some specialist hospital admissions, acute exacerbations and serious functional declines will require urgent assessment by the specialist team in Adelaide, and thus travel will be required at the time. This will be facilitated as smoothly and quickly as possible through the 'shared care' arrangements.

Throughout the 'shared care' arrangement communication of all reviews and assessments will be shared by the care partners in a timely manner and as agreed at the establishment of the 'shared care' arrangements.

**The service responses of the specialist cystic fibrosis team and linkages to other services as outlined in this integrated model are demonstrated on the following page in figure 2.**

Figure 2: Integrated Service Model Components Across Cystic Fibrosis Journey



## 4.0 Phased Implementation

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Over the next two years the model will be implemented by the specialist CF teams alongside SA Health in a phased approach. The components will be implemented according to the timeframes below. It is important to note that work towards significant aspects of the life course approach and both ambulatory and inpatient care has already commenced across the specialist teams.

### **Phase 1 (by June 2013)**

Patient charters

Lifecourse approach (including implementation of the transition to adult services pathway)

Ambulatory Care Components (Specialist service central reviews, outreach clinics, home based therapy, rapid assessment and supportive care)

Inpatient care

### **Phase 2 (BY June 2014)**

Referral pathways and service linkages

Across team clinical governance

# Attachment 1

## Cystic Fibrosis: Women's and Children's Hospital Patient Charter – Information For Parents/Carers

This Patient Charter describes the health care services people with cystic fibrosis have the right to expect and how children, teenagers and their parents/carers can contribute to gain the best possible results from their healthcare services.

Cystic fibrosis is a genetically inherited condition which is typically diagnosed by newborn screening. For most families, the diagnosis of cystic fibrosis is a shock and the amount of information about the condition and recommended treatments is at first overwhelming.

Support and advice from a team of health professionals with specialist knowledge and experience in cystic fibrosis is provided to all infants, children and teenagers and their families.

As your child grows older they will be encouraged and taught, with your support to gradually take on the management of their day to day care for themselves. They will be supported through a planned transition to adult services so that they, and you are prepared for their care management to be transferred to the adult specialist CF team at the Royal Adelaide Hospital when they reach adult age.

## Specialist Multidisciplinary Cystic Fibrosis Service

Specialist multidisciplinary CF team management of care has been shown to provide the best outcomes for people with cystic fibrosis.

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; You will be referred to specialist paediatric multidisciplinary CF team when your infant/child is diagnosed with cystic fibrosis. The specialist CF team includes a               <ul style="list-style-type: none"> <li>– consultant respiratory physician</li> <li>– clinical practice consultant</li> <li>– physiotherapist</li> <li>– dietician</li> <li>– social worker</li> <li>– psychologist</li> <li>– pharmacist.</li> </ul> </li> <li>&gt; A consultant respiratory physician will have overall responsibility for the management of your child's care.</li> <li>&gt; You will be provided with information about your child's CF condition, the latest research and the recommended treatments.</li> <li>&gt; You will be provided with training and support on how to look after your child at home.</li> <li>&gt; You will be able to access supportive counselling and be assisted with referral and linkages to other services.</li> <li>&gt; Your child will be allocated a Care Co-ordinator who will provide continuity of care, including transition from paediatric to adult services. Your Care Co-ordinator will usually be your first point of contact with the specialist CF team.</li> <li>&gt; You will work out a care plan with your Care Co-ordinator. The care plan will describe your child's individual health care needs and how these will be managed.</li> <li>&gt; The specialist CF team will be a source of information and support to other services (e.g. child care, school) that are involved in your child's care.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; The development of your child's care plan is your opportunity to discuss how your child and you interact with the CF team. It is important during this process that you describe the level of support your child and family need.</li> <li>&gt; Ask questions and seek the information you need to make the best decisions for your child's healthcare.</li> <li>&gt; Discuss any changes in your child and family's support needs with your Care Co-ordinator and make sure they are properly reflected in your child's care plan.</li> <li>&gt; Contact your Care Co-ordinator when you first notice changes in your child's symptoms, or if have any concerns about your child's health.</li> </ul>

# Attachment 1

## Hospital in the Home

Hospital in the Home (HITH) is preferred by many families if their child needs to have intravenous antibiotic therapy. It is less disruptive to your lifestyle and allows your child to continue to go to school and be at home with family and friends. It also avoids the possible risk of your child being exposed to other infections while in hospital. *(Please note: the WCH HITH program is only available to families living in the Adelaide metropolitan area).*

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; If your child needs intravenous antibiotic therapy, you can choose to have this at home, if it is agreed between you and the specialist CF team as a suitable option. <i>(Please note: the WCH HITH program is only available to families living in the Adelaide metropolitan area).</i></li> <li>&gt; You will receive support from the specialist CF team, including               <ul style="list-style-type: none"> <li>– education and training in administration of medication, use of equipment and monitoring of symptoms</li> <li>– twice daily (Mon-Fri) physiotherapy home visits and regular contact with the HITH Co-ordinator and other members of the specialist CF team as required.</li> </ul> </li> <li>&gt; The HITH Co-ordinator will arrange the supply of               <ul style="list-style-type: none"> <li>– all the necessary medications and equipment</li> <li>– any other home support services that are needed.</li> </ul> </li> <li>&gt; Your child's Care Co-ordinator will advise who to contact out of normal working hours.</li> <li>&gt; Information about your child's HITH treatment will be provided to your General Practitioner and/or other services as agreed by you.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Discuss with the HITH Co-ordinator any additional supports you need to successfully manage intravenous antibiotic therapy at home.</li> <li>&gt; Be available at agreed times for telephone and/or home visit contact by the specialist CF team, or contact the HITH Co-ordinator on XXXX XXXX, if you are not going to be available.</li> <li>&gt; Discuss with your child's Care Co-ordinator who to contact both in and out of hours.</li> </ul>

## Inpatient Care

When acutely unwell, hospital is usually the best place to be. Planned discharge aims to get your child back home as soon as they are well enough, with the supports that you need to manage your child's ongoing care.

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; Your child's admission will be streamlined and where possible your child's planned admissions will be arranged directly with the appropriate hospital ward.</li> <li>&gt; The specialist CF team will co-ordinate and monitor your child's inpatient care.</li> <li>&gt; Hospital staff will encourage children and teenagers to participate in their care, as appropriate to their abilities and understanding.</li> <li>&gt; A discharge plan will be developed in consultation with you and your child, including               <ul style="list-style-type: none"> <li>– proposed date/time</li> <li>– any home support needs</li> <li>– discharge medications</li> <li>– follow-up appointments or referrals</li> <li>– changes to your child's care plan as needed.</li> </ul> </li> <li>&gt; Information about your child's inpatient care will be provided to your General Practitioner and/or other services as agreed by you.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; While staff at the hospital aim to make your child's inpatient stay as comfortable as possible, time spent in hospital can be stressful for children and their parents. The hospital has a number of activities to entertain and amuse children during their hospital stay, but it is your loving care and support that will provide extra confidence and encouragement.</li> <li>&gt; Ask questions about the care your child is receiving.</li> <li>&gt; Support your child to ask questions and participate in their care.</li> <li>&gt; Talk with your child's Care Co-ordinator about your child's discharge plan and any information and support needs that you have.</li> <li>&gt; Ask your child's Care Co-ordinator what you and your child can do to support their recovery and successful discharge.</li> </ul>



## OUTPATIENT CLINICS

Attending outpatient clinics (usually recommended 4-6 times a year) helps you and the specialist CF team monitor your child's health and to attend to any concerns or issues.

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; The hospital will contact you to arrange a time for you to attend a specialist CF outpatient clinic                             <ul style="list-style-type: none"> <li>– these may include outreach and out of hours clinics if needed.</li> </ul> </li> <li>&gt; Your child will have a routine physical examination including lung function testing and weight and height measurements and from time to time have other basic screening tests.</li> <li>&gt; All the CF team specialists (doctors, nurses, dietician, physiotherapist, psychologist, social worker and pharmacists will be available to provide information, support and advice.</li> <li>&gt; Your child will be provided with a comprehensive annual review covering nutrition, lung function, exercise and physiotherapy assessment, medication management and growth measurements.</li> <li>&gt; The specialist CF team will arrange referrals to other services as needed.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Attend regular outpatient clinic appointments as arranged with you.</li> <li>&gt; Call XXXX XXXX to arrange another outpatient clinic appointment time, if you are not going to be available.</li> <li>&gt; Ask questions and seek the information and support that you need to manage your child's health care.</li> <li>&gt; Support your child to ask questions and participate in the care they are receiving.</li> <li>&gt; Contact your Care Co-ordinator if you have any concerns about your child's health. If necessary, they can arrange an earlier clinic appointment.</li> </ul>

## Self Management

Self management is a gradual process that is learnt over the years with the support and guidance of parents/caregivers and the specialist CF team. We aim to provide all young people with CF, the knowledge and skills to handle the physical, emotional and social aspects of living with CF and to become actively involved in managing their health care in partnership with the specialist CF team.

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; Your child will be actively encouraged to learn about CF and to be involved in decision making about their care, in ways that are appropriate to their age and understanding.</li> <li>&gt; You will be given information and support from the specialist CF team on ways that you can help your child develop self management skills.</li> <li>&gt; Your child will be encouraged and supported to manage their health care as a part of their life – family and friends, school, holidays, hobbies, sport, camps etc.</li> <li>&gt; You and your child will be offered access to information, resources and supports provided by CFSA, including access to peer and family support.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Learn about cystic fibrosis and the symptoms you need to watch out for.</li> <li>&gt; Learn about how different treatments work and how your child responds to them.</li> <li>&gt; Learn about how to encourage and support your child to develop self management skills that are appropriate to their age and understanding.</li> <li>&gt; Ask for help whenever you need it.</li> </ul>

## 24/7 CF Contact Number

From time to time, unexpected things can happen and you need to be assured that you can contact someone who knows about CF at any time.

What you can expect
<ul style="list-style-type: none"> <li>&gt; You will be able to contact someone with specialist CF knowledge at any time during the day at night, weekdays and weekends.</li> <li>&gt; From Monday to Friday (8.00am to 5pm) you can call</li> <li>&gt; Your child's Care Coordinator will discuss with you who to contact afterhours and on weekends.</li> </ul>

## Emergency Care

If your child needs urgent medical treatment you will need to go to a Hospital Emergency Department as quickly as possible, usually by ambulance.

What you can expect
<ul style="list-style-type: none"> <li>&gt; Your child will be assessed by the Emergency Medical Team.</li> <li>&gt; The Emergency Department will liaise with the on-call Paediatric Respiratory Consultant.</li> <li>&gt; Your child's Care Co-ordinator will follow-up with you and the CF specialist team.</li> </ul>

## Cystic Fibrosis: Royal Adelaide Hospital Patient Charter

This Patient Charter describes the health care services people with cystic fibrosis have the right to expect and how they and their families can contribute to gain the best possible results from healthcare services.

Up until now it is likely you have had your care provided by the specialist CF team at the Women's and Children's Hospital. Having undergone a successful, planned transition to adult services your care will now be planned with the adult CF specialist team at the Royal Adelaide Hospital.

The involvement of parents, partners and other family members in attending your clinics and participating in care planning will be a decision for you to make. Please let the team know your decision, and let them know if this changes over time.

### Specialist Multidisciplinary Cystic Fibrosis Service

Specialist multidisciplinary CF team management of care has been shown to provide the best outcomes for people with cystic fibrosis.

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; Your care will be transferred to the specialist adult multidisciplinary CF team when you and the paediatric team feel you have completed the transition process successfully. Team members include:                             <ul style="list-style-type: none"> <li>– consultant respiratory physician</li> <li>– clinical practice consultant</li> <li>– physiotherapist</li> <li>– dietician</li> <li>– social worker</li> <li>– psychologist</li> <li>– pharmacist.</li> </ul> </li> <li>&gt; A consultant respiratory physician will have overall responsibility for the management of your care.</li> <li>&gt; You will be provided with information about your CF condition, the latest research and the recommended treatments.</li> <li>&gt; You will be able to access supportive counselling and be assisted with referral and linkages to other services.</li> <li>&gt; You will be allocated a Care Co-ordinator who will provide continuity of care. Your Care Co-ordinator will usually be your first point of contact with the specialist CF team.</li> <li>&gt; You will work out a care plan with your Care Co-ordinator. The care plan will describe your individual health care needs and how these will be managed.</li> <li>&gt; The specialist CF team will be a source of information and support to other services (e.g. GP) that are involved in your care.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; The development of your care plan is your opportunity to discuss how you and the CF team interact. It is important during this process that you describe the level of support you need.</li> <li>&gt; Ask questions and seek the information you need to make the best decisions for your healthcare.</li> <li>&gt; Discuss any changes in your support needs with your Care Co-ordinator and make sure they are properly reflected in your plan.</li> <li>&gt; Contact your Care Co-ordinator when you first notice changes in your symptoms, or if have any concerns about your health.</li> </ul>

### Hospital in the Home

Hospital in the Home (HITH) is preferred by many people if they need to have intravenous antibiotic therapy. It is less disruptive to your lifestyle and it also avoids the possible risk of being exposed to other infections while in hospital. (Please note: the RAH HITH program is only available to people living in the Adelaide metropolitan area).

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; If you need intravenous antibiotic therapy, you can choose to have this at home, if it is agreed between you and the specialist CF team as a suitable option. (Please note: the RAH HITH program is only available to people living in the Adelaide metropolitan area).</li> <li>&gt; You will receive support from the specialist CF team, including               <ul style="list-style-type: none"> <li>– education and training in administration of medication, use of equipment and monitoring of symptoms</li> <li>– twice daily (Mon-Fri) physiotherapy home visits and regular contact with the HITH Co-ordinator and other members of the specialist CF team as required.</li> </ul> </li> <li>&gt; The HITH Co-ordinator will arrange the supply of               <ul style="list-style-type: none"> <li>– all the necessary medications and equipment</li> <li>– any other home support services that are needed.</li> </ul> </li> <li>&gt; Advice on who to contact after hours and how to do so.</li> <li>&gt; Information about your HITH treatment will be provided to your General Practitioner and/or other services as agreed by you.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Discuss with the HITH Co-ordinator any additional supports you need to successfully manage intravenous antibiotic therapy at home.</li> <li>&gt; To be available at agreed times for telephone and/or home visit contact by the specialist CF team, or contact the HITH Co-ordinator on XXXX XXXX, if you are not going to be available.</li> <li>&gt; Discuss with your Care Coordinator who to contact both in and out of hours.</li> </ul>

### Inpatient Care

When acutely unwell, hospital is usually the best place to be. Planned discharge aims to get you back home as soon as you are well enough, with the supports that you need to manage your ongoing care.

What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; Your admission will be streamlined and where possible any planned admissions will be arranged directly with the appropriate hospital ward.</li> <li>&gt; The specialist CF team will co-ordinate and monitor your inpatient care.</li> <li>&gt; A discharge plan will be developed in consultation with you. Including               <ul style="list-style-type: none"> <li>– proposed date/time</li> <li>– any home support needs</li> <li>– discharge medications</li> <li>– follow-up appointments or referrals</li> <li>– changes to your care plan as needed.</li> </ul> </li> <li>&gt; Information about your inpatient care will be provided to your General Practitioner and/or other services as agreed by you.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Ask questions about the care you are receiving.</li> <li>&gt; Talk with your Care Co-ordinator about your discharge plan and any information and support needs that you have.</li> <li>&gt; Ask your Care Coordinator what you can do to support your recovery and successful discharge.</li> </ul>

# Attachment 1

<b>Outpatient Clinics</b>	
Attending outpatient clinics (usually recommended 4-6 times a year) helps you and the specialist CF team monitor your health and to attend to any concerns or issues.	
What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; The hospital will contact you to arrange a time for you to attend a specialist CF outpatient clinic                             <ul style="list-style-type: none"> <li>– these may include outreach and out of hours clinics if needed.</li> </ul> </li> <li>&gt; You will have a routine physical examination including lung function testing and weight and height measurements and from time to time have other basic screening tests.</li> <li>&gt; All the CF team specialists (doctors, nurses, dietician, physiotherapist, psychologist, social worker and pharmacists) will be available to provide information, support and advice.</li> <li>&gt; You will be provided with a comprehensive annual review covering nutrition, lung function, exercise and physiotherapy assessment, medication management and growth measurements.</li> <li>&gt; The specialist CF team will arrange referrals to other services as needed.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Attend regular outpatient clinic appointments as arranged with you.</li> <li>&gt; Call XXXX XXXX to arrange another outpatient clinic appointment time, if you are not going to be available.</li> <li>&gt; Ask questions and seek the information and support that you need to manage your health care.</li> <li>&gt; Contact your Care Co-ordinator if you have any concerns about your health. If necessary, they can arrange an earlier clinic appointment.</li> </ul>
<b>Self Management</b>	
Having gained the knowledge and skills to handle the physical, emotional and social aspects of living with CF through the transition process, your self management will continue to be supported by the specialist adult CF team as your care requirements change.	
What you can expect	What you can contribute
<ul style="list-style-type: none"> <li>&gt; You will be actively encouraged to continue to learn about CF and to be involved in decision making about your care.</li> <li>&gt; You will be given information and support from the specialist CF team on ways to continue to develop your self management skills in new environments such as the workplace.</li> <li>&gt; You will be offered access to information, resources and supports provided by CFSA, including access to peer and family support.</li> </ul>	<ul style="list-style-type: none"> <li>&gt; Learn about cystic fibrosis and the symptoms you need to watch out for.</li> <li>&gt; Learn about how different treatments work and how you respond to them.</li> <li>&gt; Ask for help whenever you need it.</li> </ul>
<b>24/7 CF Contact Number</b>	
From time to time, unexpected things can happen and you need to be assured that you can contact someone who knows about CF at any time.	
What you can expect	
<ul style="list-style-type: none"> <li>&gt; You will be able to contact someone with specialist CF knowledge at any time during the day at night, weekdays and weekends.</li> <li>&gt; From Monday to Friday (8.00am to 5pm) you can call</li> <li>&gt; Afterhours and on weekends you can contact XXXX</li> </ul>	
<b>Emergency Care</b>	
If you need urgent medical treatment you will need to go to a Hospital Emergency Department as quickly as possible, usually by ambulance.	
What you can expect	
<ul style="list-style-type: none"> <li>&gt; You will be assessed by the Emergency Medical Team.</li> <li>&gt; The Emergency Department will liaise with the on-call Respiratory Consultant.</li> <li>&gt; Your Care Co-ordinator will follow-up with you and the CF specialist team.</li> </ul>	

# Appendix 1

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## Guiding Principles for Transition

1. Transition is discussed by healthcare providers with children and their families\* from diagnosis and is an accepted part of a child's care pathway.
2. Transition is actively planned, coordinated and integrated as a key component of care.
3. Transition is a shared responsibility across paediatric and adult services and is developed actively with the young person where possible, and their parents/carers.
4. The process of transition occurs within an individual's developmental context and specific circumstances, at a time of relative stability in the young person's life.
5. Developmentally appropriate health education is provided to young people and self-management skills are actively developed throughout care.
6. Services (paediatric, youth and adult) are flexible in providing care that is accessible and appropriate for young people.
7. Transition process is coordinated and supported by a skilled transition coordinator, working across a strong multi-disciplinary transition network.
8. Support is actively provided to young people and their families/carers\* to prepare for adult services and the young person's increasing independence according to individual need and circumstances.
9. Training and support is provided to care teams to ensure a focus on transitioning clients.
10. General Practitioners are partners in the transition process.
11. Transition is supported by communication and collaboration between all parties (paediatric, adult, young person, parents/carers, general practitioners), beginning with the development of an agreed transition plan and including the development of patient held note.
12. Readiness is assessed on an individual basis and in partnership with the young person and their families.

# Appendix 2

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## Cystic Fibrosis Standards of Care, Australia 2008

### Chapter 7 – Cystic Fibrosis: Transition from Paediatric to Adult Care

**Standard 1** Transition from paediatric to adult care involves a process of close cooperation between paediatric and adult specialised care teams.

**Standard 2** All CF Centres should have a transition programme incorporating active education on adult issues, i.e. fertility, and the process should engage the young person with CF and their family in a positive way.

**Standard 3** The concept of transition should be raised soon after diagnosis with more active discussions commencing around secondary school entry (12 years) and the process finishing with transfer to adult care around school leaving age (18 years).

**Standard 4** Paediatric and adult specialist care teams should meet regularly to discuss individuals in transition.

**Standard 5** The adult co-ordinator should meet individuals during the year before transfer, and the adolescent should have the opportunity to visit the adult CF Centre at this time.

**Standard 6** A comprehensive summary of medical and social issues should be available to the adult team well in advance of transfer. The local CF Association can be involved to help facilitate the process.



## For more information

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If you do not speak English, request an interpreter from SA Health and the Department will make every effort to provide you with an interpreter in your language.



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