



Australian Government

Australian Institute of  
Health and Welfare

# Selected chronic diseases among Australia's children

## Highlights

- Asthma is the most common chronic disease among Australian children aged 0–14 years. It is also a common reason for hospitalisation and is a problem frequently managed by general practitioners.
- Even though the total numbers of cases are small, diabetes (both Type 1 and Type 2) is on the rise among Australian children.
- Although cancer is relatively uncommon among children, it is the most common cause of chronic disease deaths among children.

## Introduction

Long-term illnesses and chronic diseases are commonly associated with older people and not with children. However, a small but significant number of children suffer from chronic diseases. These diseases cause stress on children and their families, and demand substantial amounts of time, energy and personal resources in order to cope with the situation (Jessop & Stein 1989).

There are many different types of chronic diseases and illnesses. Some are present at birth, while others may develop at a later stage during infancy or childhood. While some children with chronic diseases or illnesses of childhood may grow out of them later in life, most will not be able to lead normal lives in the absence of special care or management (Jessop & Stein 1989). However, with appropriate management, many children with chronic conditions can function well and live almost normal lives.

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# Selected chronic diseases among Australia's children

## ***What is a chronic disease?***

*In Australia, there is a lack of an agreed general definition of what constitutes chronic disease or illness. One definition from the United States (Center for Disease Control) states that 'a chronic disease is one that, in general terms, has a prolonged course, that does not resolve spontaneously, and for which a complete cure is rarely achieved' (NPHP 2001).*

*O'Halloran et al. (2004) used a set of criteria to define chronic conditions. They state that chronic conditions may:*

- have a duration that has lasted, or is expected to last, at least 6 months*
- have a pattern of recurrence, or deterioration*
- have a poor prognosis*
- produce consequences, or sequelae that impact on the individual's quality of life.*

This bulletin presents information on the incidence, prevalence and trends for three of the major chronic diseases among children—asthma, diabetes and cancer. In addition, information about problems managed by general practitioners is presented, as well as a summary of hospitalisations and deaths for a wider range of childhood chronic diseases including cerebral palsy, epilepsy and cystic fibrosis.

Though these conditions do not represent the full range of chronic illness among Australia's children, available prevalence data show that these cause a significant burden among the child population. Of course there are a number of other long-term conditions such as sight, hearing, allergic and musculoskeletal disorders that are also experienced by Australian children (ABS 2002a) but these are not discussed here. National prevalence and incidence data are not yet available for a number of chronic diseases, and for other conditions, the burden associated with a chronic illness may not necessarily result in hospitalisation or premature death, but may cause long-term disability.

Data sources for information about chronic disease include the National Hospital Morbidity Database, the AIHW Mortality Database, the ABS National Health Survey, the Bettering the Evaluation and Care of Health (BEACH) survey, the National Diabetes Register and the National Cancer Statistics Clearing House.

## **Definitions of selected chronic diseases affecting children**

*Asthma is a chronic inflammatory disease of the air passages causing widespread narrowing in them, obstruction of airflow, and episodes of wheezing, chest tightness and shortness of breath.*

*Diabetes (diabetes mellitus) is a chronic condition in which the body makes too little of the hormone insulin or cannot use it properly. This raises the blood level of the body's major energy source, the sugar glucose, and causes other widespread disturbance of the body's energy processes.*

- *Type 1 diabetes is a form of diabetes usually arising in childhood or youth ('juvenile onset'), marked by a complete lack of insulin and needing insulin replacement for survival.*
- *Type 2 diabetes is the most common form of diabetes, occurring mostly in people aged 40 years and over and marked by reduced or less effective insulin.*

*Cancer is a range of diseases where some of the body's cells begin to multiply out of control, can invade and damage the area around them, and can also spread to other parts of the body to cause further damage.*

*Cystic fibrosis is a life threatening genetic disorder that primarily affects the respiratory system (lungs), the digestive system (pancreas and sometimes liver) and the reproductive system. The mucus glands of people with cystic fibrosis secrete very thick sticky mucus.*

*Cerebral palsy describes a range of disabilities associated with movement and posture. 'Cerebral' refers to the brain and 'palsy' means weakness or lack of muscle control. The disorder is caused by a permanent, nonprogressive brain defect or lesion present at birth.*

*Epilepsy is a disturbance of brain function marked by recurrent fits and loss of consciousness.*

*Source: AIHW 2004, HealthInsite web site (Accessed 6/6/05).*

## **Are there any known risk factors for childhood chronic diseases?**

Research has identified many potential risk factors associated with the development of childhood chronic disease, but very few have been identified as modifiable risk factors. Evidence on the few potentially modifiable risk factors is, in many cases, inconsistent or inconclusive (AIHW 2002a). Childhood obesity, for example, while a critical risk factor for the development of chronic diseases in adulthood, is not linked in the same way to childhood chronic disease.



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As research continues into what causes chronic disease in children, there is also a need to focus on improving treatment and management practices for chronic illness. This is particularly important as inadequately managed chronic disease can seriously affect the social, psychological and physical development of children, resulting in limited education and participation opportunities as well as the potential for conditions to worsen. In addition, many studies suggest that the families of children with chronic diseases may also be adversely affected, particularly financially and psychologically (e.g. Ashton 2004; Swanston et al. 2000).

## **How do chronic conditions affect the lives of children and their families?**

Chronic diseases in childhood are significant for several reasons. An important consideration is that they occur at a time when they threaten the normal trajectory of a child's development. The care of children with chronic diseases can be extremely complex. Type 1 diabetes, for example, requires lifelong care. Good management requires a team of professionals including a GP, a diabetes educator, dietician, and others, depending on individual needs. And a child will need to learn many aspects of self-care from monitoring their diet to the injection of insulin many times a day. Management for other childhood diseases can be similarly complex and require a combination of medical and other services (Stein 2001).

Care for a child with chronic disease is frequently very costly and the costs are magnified because the illness continues over a long period of time. The cumulative toll on children and their families is often high in social, psychological and economic terms. Also, because children with chronic diseases are still developing, physically and emotionally, their care needs are very different from those of chronically ill adults (Stein 2001).

Just as the socioeconomic status of the family can influence child health, it is also an important factor in the outcome of a chronic childhood illness. Family composition, and economic, social and personal resources, greatly influence the ability of a family to meet the needs of a chronically ill child (Jessop & Stein 1989).

Finally, there is evidence that chronically ill children, and their families, are at greater risk of developing psychological and emotional difficulties than other children and their families. The Ontario Child Health Survey estimated the risk of psychiatric disorders for those with chronic conditions to be twice as high as that for healthy children (Cadman et al. 1987). This consequence of chronic illness is preventable.

The majority of children overcome the obstacles that chronic illness presents. However, it is important to normalise as much as possible the life experiences of these children, minimising periods of hospitalisation, maintaining contact with family and friends and maximising participation in education and other activities.

## Asthma

Asthma is a major disease burden among Australian children. In 2002–03 asthma was the most common reason for hospitalisation for children aged 0–14 years and the most common long-term condition among children aged 0–14 years (AIHW 2005). In addition, asthma is a common cause of absence from school, with 24% of children with asthma reporting missing a day of school within the last 2 weeks, compared with 16% of children without asthma (ABS 2004).

## Prevalence

The 2001 Australian Bureau of Statistics (ABS) National Health Survey (NHS) estimated the prevalence of asthma among children in 2001 (Table 1). Prevalence estimates are based on whether children have ever been diagnosed with asthma and still have asthma as a current condition.

- In 2001, the overall prevalence of asthma among Australian children aged 0–14 years was 13.3%.
- Prevalence for boys was highest among those aged 5–9 years (19.8%). Prevalence of asthma among girls was highest among those aged 10–14 years (15%). For young people older than 14 years this sex pattern is reversed and asthma tends to be more common among females than males (ACAM 2003).

**Table 1: Prevalence of current asthma, by age group and sex, Australia, 2001**

	Males		Females	
	Number	Per cent	Number	Per cent
<b>Age group</b>				
0–4	56,761	8.7	47,947	7.7
5–9	136,131	19.8	76,291	11.7
10–14	113,312	16.6	97,037	15.0
<b>Total 0–14</b>	<b>306,204</b>	<b>15.1</b>	<b>221,275</b>	<b>11.5</b>

*Note:* Current asthma as measured by the 2001 NHS is defined by having both doctor-diagnosed asthma and answering yes to the question ‘do you still have asthma?’. It is possible that prevalence is underestimated due to variations in the way people interpreted this question.

*Source:* ABS National Health Survey 2001.



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## Trends

Data from previous ABS National Health surveys show that between 1989–90 and 1995, the prevalence of asthma increased in children aged 0–14 years—by 12.3% for males and 25.4% for females (ABS 1999). However, this increase may be explained by the introduction of the National Asthma Campaign in 1990 which led to increased awareness and vigilance by doctors and patients, resulting in increased diagnosis and reporting of the disease (Wilson et al. 2003). A comparison of asthma prevalence trend studies shows varying results. Although there is general agreement that there was an increase from 1982 to 1992, trends after this time are not clear (ACAM 2003).

## Population groups

There are limited data about the prevalence of asthma among different population groups. Asthma prevalence is higher among people born in Australia than among those that have recently migrated to Australia (ACAM 2003). Data from the NHS show little difference in the proportion of Indigenous and non-Indigenous children with asthma—15% of Indigenous versus 13% of non-Indigenous children aged 0–14 years were reported to have asthma (ABS 2002b). However, evidence on differences in prevalence related to remoteness or socioeconomic status is inconclusive at this stage (ACAM 2003).

## Diabetes

Diabetes is a disease which can cause serious health problems if undetected or inadequately managed. Type 1 diabetes (which accounts for 98% of diabetes in children) can result in serious complications if untreated, including blindness, kidney failure, peripheral vascular disease and foot problems. It is a difficult condition to manage, particularly in children, and requires a careful balance of diet, exercise and insulin intake (AIHW 2002b).

Type 2 diabetes is caused by reduced insulin production or the inability of the body to use insulin properly and is associated with being overweight or obese. The disease is managed through diet, exercise, oral medication and, as necessary, with insulin. Type 2 diabetes is less common in children, usually developing in people aged over 40. However, there is evidence that as obesity is increasing in children and young people, the incidence of Type 2 diabetes in children is also increasing (McMahon et al. 2004).

Although the prevalence of Type 1 diabetes in the Australian population is relatively low (around 0.5% in 2001) (AIHW 2004), recent studies are showing an increase in the incidence of Type 1 diabetes at the rate of 3% per year (Handelsman & Jackson 1999; Haynes et al. 2004; Craig et al. 2000), making it the fastest growing chronic disease amongst Australian children (AIHW 2002b).

## Incidence

Incidence data on diabetes come from the National Diabetes Register (NDR). The NDR is a database of people who have insulin-treated diabetes, and who commenced using insulin after January 1999. Coverage for children is almost 100% because data are obtained from two different sources (Diabetes Australia and the Australian Paediatric Endocrine Group (APEG)). The incidence of Type 1 diabetes during the years 2000 and 2001 is shown in Table 2.

**Table 2: New cases of Type 1 diabetes amongst children aged 0–14 years reported during 2000 and 2001.**

Sex and age at first insulin use	Number	Rate <sup>(a)</sup>
<b>Males</b>		
0–4	187	14.2
5–9	279	20.1
10–14	365	26.4
<i>Total males 0–14</i>	<i>831</i>	<i>20.3</i>
<b>Females</b>		
0–4	143	11.4
5–9	280	21.2
10–14	311	23.6
<i>Total females 0–14</i>	<i>734</i>	<i>18.9</i>
<b>Total children 0–14</b>	<b>1,565</b>	<b>19.6</b>

(a) Average annual number per 100,000 children.

Source: AIHW 2003b.

- During 2000 and 2001, 1,565 children were diagnosed and registered with Type 1 diabetes.
- The distribution of diabetes between girls and boys was relatively even; approximately 52% of children with diabetes were boys.

## Trends

While Type 1 diabetes represents the majority of diabetes in childhood, the incidence of Type 2 diabetes is also becoming a concern. A recent study of Western Australian children aged up to 17 years found an average annual increase of 27% in the diagnosis of Type 2 diabetes in this age group during 1990–2002 with a total of 43 cases over the period (McMahon et al. 2004). The rise in the incidence of Type 2 diabetes has been associated with the parallel increase in obesity among children. Type 2 diabetes is quite different from Type 1, which has no known modifiable risk factors.

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## Cancer

Cancer is a chronic disease which has a severe impact on all aspects of a child's development and which poses many hardships both for the children and for the family and friends of children diagnosed with cancer. Cancer is relatively uncommon among children, with less than 1% of all cancers occurring in children in 2001. In 2003, 16% of deaths among children aged 1–14 years were due to cancer (few deaths from cancer occur among infants).

Cancer was made a National Health Priority Area in 1996 in response to concerns over the rising incidence of many cancers and the burden of death and disability this was placing on the Australian population. The statistics in the following section show a small but significant rise in the incidence of cancer among Australian children.

## Incidence

Information about the incidence of cancer among children is obtained from the National Cancer Statistics Clearing House (Table 3).

The cancer incidence rates in 2001 were 15.8 new cases per 100,000 for boys and 14.4 per 100,000 for girls. Incidence was highest for children aged 0–4 years (22.1 per 100,000 children).

The most common types of new cases of cancer among children aged 0–14 years in 2001 were leukaemia (6.0 per 100,000 boys, 5.3 per 100,000 girls) and brain cancer (3.3 per 100,000 boys, 2.5 per 100,000 girls). These accounted for 57% of cancers diagnosed in children in 2001.

**Table 3: Number of new cancer cases for children aged 0–14, selected cancers and total cancers, by sex and age group, 2001**

Type of cancer	Males			Females			Total
	0–4	5–9	10–14	0–4	5–9	10–14	
Leukaemia	63	33	26	47	30	26	225
Brain and other central nervous system	25	28	15	27	13	8	116
All lymphomas	9	13	24	3	8	11	68
Connective and other soft tissue	13	3	2	11	1	7	37
Kidney, ureter and urethra	11	1	0	15	4	1	32
Other endocrine glands	10	3	0	7	1	0	21
Bone and articular cartilage	0	5	2	2	4	8	21
Eye	9	1	0	7	1	2	20
Skin-melanoma	0	0	6	1	6	6	19
<b>All cancers (except NMSC)</b>	<b>156</b>	<b>89</b>	<b>79</b>	<b>128</b>	<b>72</b>	<b>79</b>	<b>603</b>

Note: NMSC Non-melanocytic skin cancer.

Source: National Cancer Statistics Clearing House.

- In 2001, 603 children aged 0–14 years were diagnosed with cancer.
- The most common types of cancer in children aged 0–14 years during 2001 were leukaemias, and cancer of the brain and central nervous system (CNS). Cancers in connective and other soft tissue as well as kidney cancer were some of the other common types of childhood cancer.
- Cancers are slightly more common in boys than in girls, with almost 54% of new cases of cancer occurring in males.

### **Trends**

Between 1982 and 2001, the age standardised incidence rate for all cancers combined (excluding non-melanoma skin cancers) increased by an average of 0.6% per year for children aged 0–14 years.

The 5-year survival rate from leukaemia increased significantly from 62.4% to 69.7% between 1982–86 and 1992–97. Although there was a slight increase in the 5-year survival rate for children with brain cancer, this increase was not statistically significant.

### **Hospitalisation and deaths due to chronic diseases**

The AIHW National Hospital Morbidity Database was used to obtain information on the reason for hospitalisations of children. In this bulletin, only information on the principal diagnosis—the diagnosis established to be the problem that was chiefly responsible for the patient's episode of care in hospital—is presented. While other associated diagnoses may also be recorded for each hospital episode, these data are not presented.

Hospital records are for 'separations', not individuals, and as there can be multiple admissions for the same individuals, hospitalisation rates do not usually reflect the incidence or prevalence of the chronic disease or condition in question. Hospitalisation numbers can also be affected by admission practices and access, as well as the incidence or prevalence of the disease or condition. Hospitalisations for a number of common chronic diseases among children are presented in Table 4.

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**Table 4: Hospitalisation rates for children aged 0–14 years for selected chronic diseases, 2002–03 (number of separations per 100,000 children)**

	Asthma	Cancer	Epilepsy	Diabetes	Cerebral palsy	Cystic fibrosis	All causes
<b>Sex and age group</b>							
<b>Boys</b>							
<1	396.0	124.8	129.0	0.8	11.6	71.1	63,079
1–4	1,497.2	238.4	117.9	39.2	50.2	28.9	19,613
5–9	470.0	176.5	89.3	41.2	57.1	17.6	10,426
10–14	187.3	127.9	62.6	93.4	38.8	33.6	8,420
<i>Total</i>	<i>631.4</i>	<i>172.4</i>	<i>89.9</i>	<i>56.2</i>	<i>46.2</i>	<i>29.4</i>	<i>15,458</i>
<b>Girls</b>							
<1	88.3	37.1	70.6	2.8	3.6	25.4	49,146
1–4	390.2	94.6	53.6	15.0	16.5	14.0	14,561
5–9	129.1	60.0	33.4	25.9	18.7	11.9	7,827
10–14	70.7	56.2	27.1	45.7	8.3	23.2	6,906
<i>Total</i>	<i>173.4</i>	<i>66.2</i>	<i>38.7</i>	<i>28.5</i>	<i>13.6</i>	<i>17.1</i>	<i>11,875</i>
<b>Persons</b>							
<1	189.2	65.9	89.7	2.2	6.2	40.4	56,284
1–4	752.9	141.7	74.7	22.9	27.6	18.9	17,151
5–9	240.7	98.1	51.7	30.9	31.3	13.7	9,161
10–14	108.9	79.7	38.7	61.4	18.3	26.6	7,682
<b>Total</b>	<b>323.4</b>	<b>101.0</b>	<b>55.5</b>	<b>37.6</b>	<b>24.3</b>	<b>21.1</b>	<b>13,712</b>

Source: National Hospital Morbidity Database.

- The hospitalisation rates for chronic conditions among boys were consistently higher than the rates for girls.
- Hospitalisation rates were generally higher among children aged 1–4 years, though for some conditions such as diabetes and cystic fibrosis the highest number of hospitalisations were for 10–14 year old children and infants, respectively.
- Rates of hospitalisation for asthma were much higher than those for any other chronic condition.

The AIHW Mortality Database was used to extract data on the number of deaths among children where the underlying cause was a chronic disease. Overall deaths from chronic diseases are relatively low (Table 5).

**Table 5: Number and death rates for selected chronic diseases among children aged 0–14 years, 1994 to 2003**

	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003
<b>Number</b>										
Cancer	162	144	142	138	154	122	105	118	124	102
Cerebral palsy	36	30	29	20	37	28	25	24	25	18
Epilepsy	13	18	18	14	13	10	13	11	8	15
Asthma	12	20	13	15	12	13	12	5	9	7
Diabetes	3	1	2	2	1	1	1	0	1	2
Cystic fibrosis	10	12	9	18	11	10	6	11	3	0
<i>All causes</i>	<i>2,317</i>	<i>2,254</i>	<i>2,252</i>	<i>2,067</i>	<i>1,975</i>	<i>2,069</i>	<i>1,931</i>	<i>1,911</i>	<i>1,882</i>	<i>1,775</i>
<b>Number per 100,000 children</b>										
Cancer	4.3	3.8	3.8	3.6	4.1	3.2	2.8	3.1	3.3	2.7
Cerebral palsy	1.0	0.8	0.8	0.5	1.0	0.7	0.7	0.6	0.7	0.5
Epilepsy	0.3	0.5	0.5	0.4	0.3	0.3	0.3	0.3	0.2	0.4
Asthma	0.3	0.5	0.3	0.4	0.3	0.3	0.3	0.1	0.2	0.2
Diabetes	0.1	0.0	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.1
Cystic fibrosis	0.3	0.3	0.2	0.5	0.3	0.3	0.2	0.3	0.1	0.0
<i>All causes</i>	<i>60.0</i>	<i>58.0</i>	<i>57.6</i>	<i>52.6</i>	<i>50.2</i>	<i>52.4</i>	<i>48.7</i>	<i>47.9</i>	<i>47.2</i>	<i>44.6</i>

Source: AIHW Mortality Database.

- For many conditions death rates have declined over time. For example, the death rate from cancer for children aged 0–14 years reduced by over a third between 1994 and 2003.
- Though asthma is a major cause of hospitalisations for children, deaths from asthma are relatively rare.
- Cancer was the most common cause of death from chronic disease. Over the period 1994 to 2003, deaths from cancer among children accounted for more than twice the number of all other deaths from chronic disease added together.

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## Chronic conditions seen in general practice

The BEACH Program is a rolling survey that samples around 1,000 general practitioners each year on the details of 100 consecutive consultations per general practitioner. It includes information on the reasons patients present, as well as the problems managed, referrals, treatments, tests and investigations ordered and procedures carried out (AIHW: Britt et al. 2004). Information on the management of chronic problems by general practitioners for patients aged less than 15 years in general practice is presented in Table 6. Chronic conditions were defined using a customised grouping of codes from the International Classification of Primary Care (for details see O'Halloran et al. 2004).

Between January and December 2004 there were 10,937 encounters with patients aged 0–14 years, at which 12,771 problems were managed. Chronic problems managed numbered 1,081 (8.5% of all problems). Extrapolation to all consultations with children in general practice across Australia suggests that the general practitioners manage chronic conditions in children on about 800,000 occasions per year.

**Table 6: Top 15 chronic conditions among children aged 0–14 years, managed by general practitioners, January to December 2004**

Problem managed	Per cent of chronic problems managed by GPs
Asthma	47.9
Oesophagus disease	7.0
Dermatitis, atopic eczema	4.2
Hyperkinetic disorder	3.8
Acne (chronic)	3.6
Hypertrophy tonsils/adenoids	2.6
Migraine	2.1
Epilepsy	2.0
Dermatitis, seborrhoeic	1.9
Depressive disorder	1.4
Obesity	1.4
Congenital anomaly cardiovascular	1.3
Heart/arterial murmur NOS	1.3
Anaemia (chronic)	1.2
Diabetes	1.0

NOS Not otherwise specified.

Source: BEACH survey, unpublished data.

- Asthma was the most common childhood chronic condition managed by general practitioners between January and December 2004 accounting for almost half (48%) of all chronic problems managed.
- Oesophageal disease, dermatitis (allergic eczema), hyperkinetic disorder and chronic acne were also commonly managed among children (accounting for a further 19% of chronic problems).

## Conclusion

Since the 20th century, chronic diseases have begun to dominate the health scene (AIHW 2002a). While the impact of this increase has mostly been witnessed among older people in our population, children too are experiencing higher levels of chronic illness than in the past.

While there is no evidence to suggest that the prevalence of asthma is still on the rise, it continues to be a major cause of chronic illness among children. Among chronic conditions experienced by children it is a leading cause of hospitalisations and problems managed by general practitioners.

Cancer remains the leading cause of death due to chronic disease among children. Fortunately, child deaths due to chronic disease are relatively low and death rates have been declining over the last 10 years.

Nevertheless, it is important to continue monitoring the incidence and prevalence of chronic conditions among children to identify emerging trends, and to minimise and avoid where possible the level of hospitalisation, disability and premature mortality they may cause.

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