



ndcs
every deaf child

Information for families

Meningitis and childhood deafness




**The
Meningitis
Trust**

Our vision is of a
world without barriers
for every deaf child.

pg	Content
4	Introduction
4	What is meningitis?
5	The ear, hearing and meningitis
	Sensori-neural (or nerve) deafness
	Conductive deafness
7	Balance
8	Levels of deafness
11	Hearing tests
	Objective hearing tests
	Otoacoustic emissions (OAE)
	Auditory brainstem response (ABR)
	Behavioural tests
	Visual response audiometry (VRA)
	Pure tone audiometry (PTA)
	Air- and Bone-conduction
	Speech discrimination tests
	Hearing tests and children with complex needs
15	How will deafness affect my child?
17	How will I communicate with my child?
18	Hearing aids and cochlear implants
19	Ossification
20	Pneumococcal vaccination
21	Equipment for deaf children
22	Specialist education support services
23	FM systems
24	Useful contacts
26	References

Introduction

This booklet has been written for parents of children who have had meningitis. Deafness is the most common after-effect of meningitis. Approximately one in ten children who survive meningitis develops deafness as a result of the illness. This booklet aims to provide information on the hearing tests that are carried out following meningitis, the effects of any deafness, what can be done to help and the support that is available.

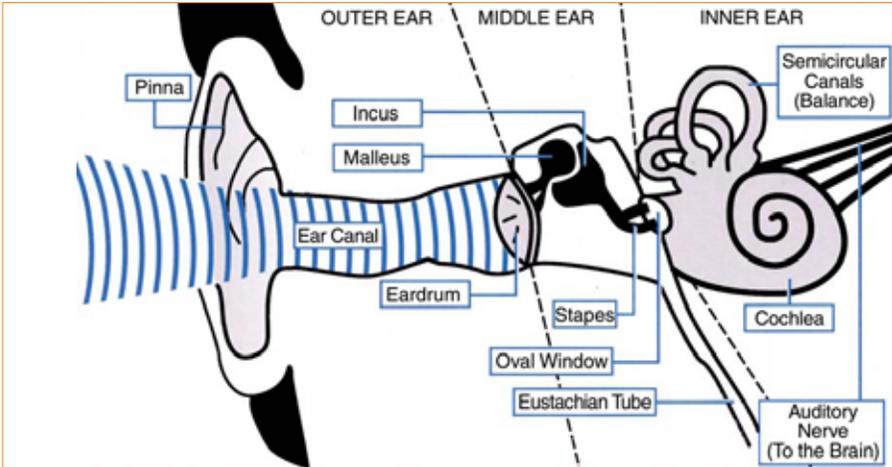
This booklet may also be helpful to mainstream teachers who have children with deafness following meningitis in their class.

What is meningitis?

Meningitis is inflammation of the meninges (membranes) that surround and protect the brain and spinal cord. It is usually caused by a bacterial or viral infection.

Meningitis can affect anyone, of any age, at any time. However babies, toddlers and children under five years are the group most at risk for meningitis, with young people aged 15-19 years the next most likely to suffer meningitis.

For more information contact the Meningitis Trust's Freephone 24-hour nurse-led Helpline on 0808 80 10 388 or visit their website at www.meningitis-trust.org



The ear, hearing and meningitis

Sensori-neural (or nerve) deafness is the type of deafness that can follow on from meningitis. Sensori-neural deafness happens when there is a fault in the inner ear (most often because the hair cells in the cochlea are not working properly) or the auditory (hearing) nerve that carries sound signals to the brain. Sensori-neural deafness is permanent. Meningitis can cause sensori-neural deafness in a number of ways. The most common cause is the infection spreading into the cochlea damaging the hair cells. Another possible cause is inflammation of the auditory nerve. Deafness can range from mild through to profound and can affect one or both ears. See pages 8–9 to find out more about what these levels of deafness mean.



Conductive deafness happens when sound cannot pass efficiently through the outer and middle ear to the cochlea and auditory nerve. The most common reason for conductive deafness in children is glue ear. Glue ear is a build up of fluid in the middle ear that makes it harder for sound to pass through to the inner ear. Glue ear is usually temporary and often clears up on its own without needing any treatment. However, for some children glue ear may persist longer term. Although meningitis doesn't cause glue ear, because it is so common during childhood it is possible that a child may have a bout of it at some point and it may even be present when their hearing is first tested following the illness.

For more information about glue ear and various treatments available, read the NDCS leaflet *Glue Ear: A guide for parents*.

Balance

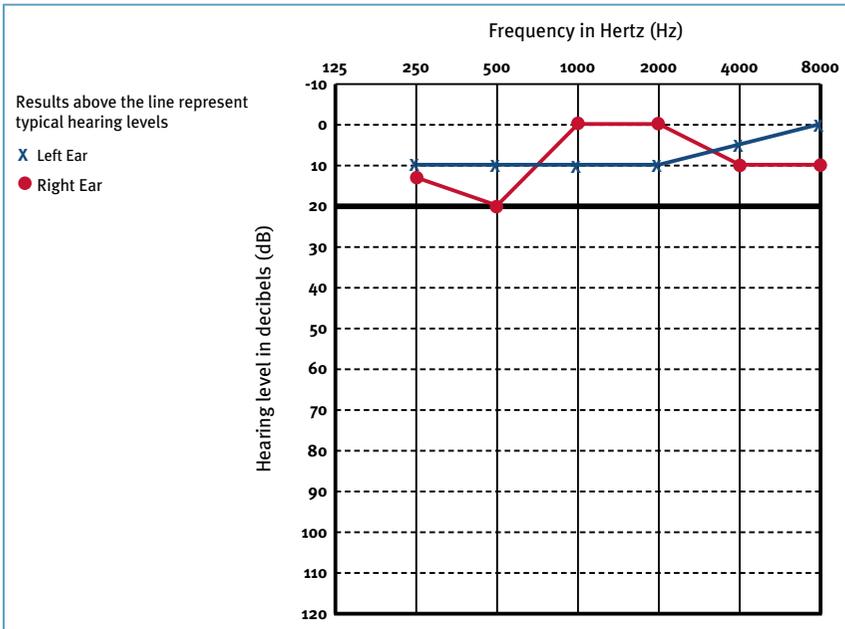
The brain uses information from the eyes (what we see), our body (what we feel) and the inner ear to balance. The semicircular canals in the inner ear are three tubes, filled with liquid and movement-sensitive hair cells. As we move, the fluid moves. This creates signals that are sent to the brain about balance. In addition to deafness, meningitis can also cause balance problems if the infection affects the semicircular canals. Older children may experience a feeling of dizziness and imbalance. In younger children balance problems may make it difficult for them to learn to do tasks that require balance such as sitting and walking. However, the brain is often able to compensate for a weak vestibular system, and children often develop good mechanisms for managing any balance problems on a day-to-day basis.

Balance function assessment, safety advice and specialised physiotherapy may be helpful for children with balance problems. For further information on the balance system, testing and disorders, read the NDCS factsheet *Balance and Balance Disorders*.

Levels of deafness

Some of your child's test results will be written on a chart like the one below, known as an audiogram. It shows you how loud a sound has to be, and at what frequency, before your child can hear it. Your child's test results may be plotted on one chart as below or two charts, side by side, for each ear separately.

This audiogram shows the level and range for a person with typical hearing levels.

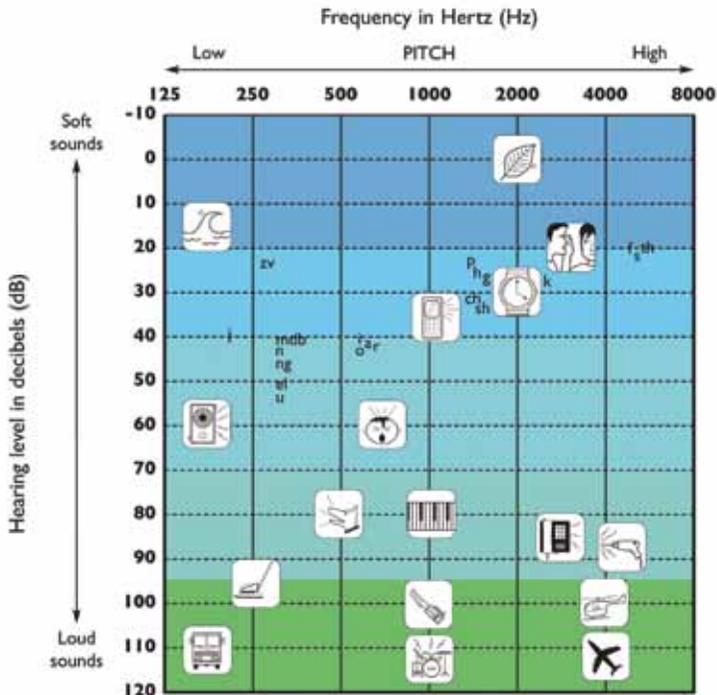


Crosses always indicate results for the left ear, and circles for the right ear. Your child may be deaf in one ear (unilateral deafness) or both ears (bilateral deafness). If your child is deaf in both ears, the deafness may be similar in both ears (symmetrical deafness) or different in each ear (asymmetrical deafness).

Your child's deafness may also be described as high frequency or low frequency, measured in hertz (Hz). We commonly think of frequency as the pitch of a sound. A piano keyboard runs from low-pitch on the left to high-pitch sounds on the right and the audiogram is the same.

There are different levels of deafness. These can be described as a decibel (dB) hearing level (how loud a sound has to be for your child to hear it) or described using terms such as 'mild', 'moderate', 'severe' or 'profound'. The very quietest sounds are at the top of the chart, getting louder as you look down the page.

Audiogram with visual representation of the loudness and pitch of a range of everyday sounds



On the audiogram on page 9 there are pictures of common sounds that give us an idea of loudness and frequency. There are also speech sounds drawn on the chart, and you can see that all the sounds of speech cover a range of frequencies. Try saying some of the speech sounds out loud while looking at the chart. The sounds m, b, and d are on the left-hand side and part way down the chart, meaning that they are lower frequency and slightly louder than say f, s, and th, which are higher in frequency and much quieter. So it is important to be able to hear sounds at a quiet level, across the frequency range, to be able to hear all the sounds of speech clearly.

Ask your child's audiologist to explain to you your child's hearing test results and what they mean for your child's ability to hear speech.



Hearing tests

It is recommended that all children who have had meningitis are offered a hearing test within four weeks of being well enough to undertake testing, and preferably before they are discharged from hospital. Deafness usually happens early on in the course of the illness and it may be noticeable to the family before the first hearing test. If the deafness is less severe it may not be as immediately obvious. It is therefore important that children are tested early. Sometimes the deafness can deteriorate (get worse) or fluctuate (change over time) in the early days but it normally stabilises during the first few months following the illness. You may then be offered several appointments to monitor the hearing over time but if you have any concerns about your child's hearing or feel that their hearing has changed, you can ask for another appointment.

It is possible to test the hearing of all children from birth onwards. There are a variety of tests that can be used to find out how much hearing your child has. The tests used will depend on your child's age and stage of development.

All babies in the UK are offered a routine hearing screen within weeks of birth. Babies who have had meningitis during the newborn period will not be offered the routine screen and will instead be referred directly to an audiologist for more detailed testing.

If your child does have a hearing loss, your local audiology and education services will provide support for you and your child (see page 22).

Objective hearing tests

The **Otoacoustic emissions (OAE)** test works on the principle that a healthy cochlea will produce a faint response when stimulated with sound. A small earpiece (containing a speaker and microphone) is placed in the child's ear. A clicking sound is played and if the cochlea is working properly, the earpiece will pick up the response which is recorded on a computer. A poor response to an OAE test does not necessarily mean that a child is deaf. Background noise, an unsettled baby/child, or fluid in the ear can all make it difficult to record the tiny response.

During an **auditory brainstem response (ABR)** test the audiologist will place three small sensors and a set of headphones on the child's head. For an accurate result, the child must be very still and quiet throughout the test. In young babies the test can be carried out while they are sleeping. In slightly older children, a light sedative or an anaesthetic may be offered. This test measures whether sound is being sent from the cochlea and through the auditory nerve to the brain. In very young children or children who are not developed enough to have behavioural hearing tests, the results of the ABR test can be used to accurately fit hearing aids if these are necessary. In older children this test may be used to confirm the results of their behavioural test.

Behavioural tests

As children get older, their audiologist will get more information about their hearing using behavioural tests. These tests use toys and play as part of the assessment and involve the child listening for a variety of sounds as part of a game.

Visual response audiometry (VRA) is suitable for children from six months to about two-and-a-half years. Using a machine called an audiometer, sounds of different frequencies and loudness are played through speakers. When the child hears the sound, they will turn their head and a visual ‘reward’ is activated, such as a toy lighting up or a puppet moving. The test can check the full range of hearing but does not give specific information about each ear. If your audiologist feels it is important to get information about each ear individually, this test can be done with small earphones.

From about the age of three, children are actively involved in **pure tone audiometry (PTA)** testing by using a technique known as conditioning. Younger children are shown how to move a toy (for example, putting a peg into a board) each time they hear a sound. Older children are asked to respond to sounds by saying yes or pressing a button. The sounds come through headphones, earphones placed inside the child’s ear, or sometimes through a speaker (when the test is known as soundfield audiometry).

All of the tests above are described as testing using **air-conduction** (that is, sounds passing through the ear canal and middle ear before reaching the cochlea). ABR, VRA and PTA can also be tested using **bone-conduction**. A small vibrating device is placed behind the child’s ear. This passes sound directly to the inner ear through the bones in the head. This technique is useful for identifying whether a hearing loss is conductive or sensori-neural.

Speech discrimination tests check the child's ability to hear words at different listening levels. The tester asks the child to identify toys or pictures, or to copy words spoken by themselves or from a recording. From this the tester can assess the quietest level at which the child can correctly identify the words used.

Hearing tests and children with complex needs

The tests used will depend on the child's age as well as their stage of development. It should be possible to test the hearing of any child, whatever their stage of development, but it is more likely that several different tests will need to be done to get a clear picture of any hearing difficulty. Objective tests (such as OAE and ABR) do not need a child to respond to a sound in order to get a result. However, the child needs to be very still and quiet throughout the test, which may mean they need a light sedative or an anaesthetic.

Some children with complex needs may have to be tested using techniques that are normally used with younger children. If your local audiology service is not confident about testing your child, you can ask to be referred to another centre with more experience of testing children with complex needs.



How will deafness affect my child?

The ways that your child will cope with their deafness will vary greatly. The issues for a young baby will be very different from those of a teenager. If you have a good understanding of your child's deafness, it will help you when you are explaining it to them (if they are old enough) or to other people involved with your child. If you have a baby or young child, your most important consideration may be finding a way of communicating with them. You may need to make decisions about hearing aids, cochlear implants, or support at nursery. It is important that you have access to the full range of information so that you can make the choices that are right for you and your family. Your local education and audiology services can help you to find the information that you need.

You may also find that your child's behaviour has changed. Their attention span may be shorter, or they may have temper tantrums or become more clingy. This may be as a result of any deafness and frustration caused by difficulties communicating or may be related to having been through a serious illness. Other children in your family may also become unsettled if your child is getting a lot of the family's time and attention. This can present new challenges for you. A serious illness, such as meningitis, can have a deep emotional effect on any child. For an older child or teenager, this may mean that they need extra help to find new ways of communicating with you, and that they take a long time to accept their deafness. It is important that they have an opportunity to understand how their deafness will affect their life, and to talk about how they are feeling. Your child's school or college should also be able to tell you about the extra support they can provide when your child returns to education.

For access to professional support services and specialist information about the after-effects of meningitis, phone the Meningitis Trust's Freephone 24-hour nurse-led Helpline on 0808 80 10 388.

For more information and support about all aspects of childhood deafness and the choices you have, phone the NDCS Freephone Helpline on 0808 800 8880 (voice and text).

How will I communicate with my child?

Deaf children can learn to communicate through sign language or spoken language, or a combination of both. If your child is a baby, you will also be communicating by using your face, voice and body to show love and let your child know that you are there. In this case you have time to get the full range of information on the different communication approaches available. If your child had already started to develop language before having meningitis, you will need to have information and advice on the best way to help your child to continue to develop language. You may also need to think about other issues, such as the support available locally, the way that your family communicates at the moment, and whether the method of communication you choose is suitable for your child's abilities or health.

It is important to remember that you do not have to make a choice for life – the communication method you choose may change as you learn more about your child's needs and preferences. If you have an older child or teenager, quickly finding a way of communicating with them is vital for their emotional well-being and confidence. There are many different communication aids available. As well as making sure they get the most out of their hearing aids or cochlear implant, they may be able to use:

- voice to text software for computers
- subtitles on television, DVDs and in cinemas and theatres
- notetakers and communication support workers in school
- textphones that give access to phone calls.

For more information see the NDCS booklets *Communicating with Your Deaf Child* and *Technology at Home*



Hearing aids and cochlear implants

Hearing aids are useful for children with most levels of hearing loss. The type of hearing aid that will be suitable for your child will depend on the type of hearing loss they have. Hearing aids can help your child to make sense of speech and a wide range of sounds. Children who have a severe to profound deafness and cannot hear the full range of speech sounds with hearing aids may be a candidate for cochlear implants. A cochlear implant is different from a hearing aid. It provides a sensation of hearing by directly stimulating the auditory nerves using electrical signals. The implant has two parts – a receiver which is implanted surgically, and an outside part which is worn like a hearing aid. The decision to have a cochlear implant is an important one. Children have to be referred to a specialist centre to be assessed before the decision is made to go ahead. It is important that you and your child feel that you have all the information and enough time to make a decision about the best options.

For more information on hearing aids and cochlear implants read the NDCS booklets *Hearing Aids: Information for families* and *Cochlear Implants: Information for families*.

Ossification

Ossification is a process that can occur after meningitis. It can cause new bone to grow in the cochlea. If you are considering a cochlear implant for your child, ossification can make it more difficult to have the electrodes of the receiver package surgically inserted. However, it rarely prevents it and you should discuss this with the specialist involved. A CT or MRI scan will be carried out to assess the amount of any ossification. The extent of any ossification may impact on how much benefit children receive from their cochlear implants. Therefore children who have had meningitis that has caused a severe to profound deafness should be offered a 'fast-track' assessment for cochlear implants. Following assessment and the decision that they are suitable candidates children are usually offered bilateral cochlear implants (one in each ear).

Having two implants offers benefits for children such as improved listening in background noise and localisation (working out which direction sounds come from). Additionally for children who have had meningitis it can be difficult to tell exactly which ear will benefit most from a cochlear implant so having two implants put in at the same time will ensure that the most receptive ear is implanted.



Pneumococcal vaccination

If your child is assessed as a suitable candidate for a cochlear implant you will be advised that your child should have a pneumococcal vaccine before surgery. This is because implanting the electrode in the cochlea might slightly increase your child's risk of catching pneumococcal meningitis. This risk is very small. It is advised that the pneumococcal vaccine is given to all existing and prospective cochlear implant recipients, including those who have previously suffered from pneumococcal meningitis or a pneumococcal infection. The vaccine is usually given by your GP.





Equipment for deaf children

There is a wide range of equipment available which can help your child to be aware of what is happening around them and help them to be independent. Doorbells, alarm clocks and phones can all be connected to a flashing light to alert your child. If your child has difficulty hearing the phone, they may be able to use an amplified phone (a phone with a built-in amplifier to increase the volume) or a textphone. If your child benefits from using hearing aids or a cochlear implant, they may be able to use a loop system or other devices to help them listen to the TV without turning up the volume. Or they may prefer to watch programmes with subtitles. DVDs are often available with subtitles.

For more information on equipment for deaf children read the NDCS booklet *Technology at Home*.

Specialist education support services

Once permanent deafness has been diagnosed, your child should be referred to the education authority's specialist hearing impairment service. A Teacher of the Deaf will advise you on how you can support your child's language and communication development, use of hearing aids, will provide information on the options for early years or school placement, and will be responsible for ensuring your child has any appropriate support they need to ensure they can make friends, hear what is going on and learn and progress.

Contact NDCS for useful publications with further advice for schools and teachers.

You may also be offered an appointment with a speech and language therapist if required. For more information read the NDCS booklet *Deaf Children and Speech and Language Therapy*.

In addition to hearing loss, the after-effects of meningitis can be complex, affecting children both physically and mentally. Evidence from a recent study commissioned by the Meningitis Trust shows that; children are more likely to have a low IQ, problems with memory, organisation and planning; as well as being significantly more likely to have anxiety and behavioural disorders. These after-effects can have a huge impact on children's education, but are not always recognised as complications of the disease. For more information contact the Meningitis Trust Helpline on 0808 80 10 388.



FM systems

Some deaf children use additional equipment in school to help them hear the teacher and their peers better. Personal FM systems (commonly known as radio aids) help overcome problems of listening when:

- there is unwanted background noise
- sounds are echoing around the room (reverberation)
- there is a distance between the person who is speaking and the deaf child.

Radio aids consist of a transmitter worn by the teacher, and a receiver worn by the child that plugs into the bottom of their hearing aids or cochlear implants bringing the teachers voice directly to the child regardless of where they are in the room.

Ask your Teacher of the Deaf for more information or see the NDCS booklet *Radio Aids: An introductory guide*.

Useful contacts

The National Deaf Children's Society (NDCS)

15 Dufferin Street, London EC1Y 8UR

Freephone Helpline: 0808 800 8880 (voice and text)

Fax: 020 7251 5020

Email: helpline@ndcs.org.uk

www.ndcs.org.uk

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people. We represent the interests and campaign for the rights of all deaf children and young people from birth until they reach independence.

If you would like to talk to us in a language other than English, tell us your name, phone number and the language you would like to talk to us in. We will call you back with an interpreter within a few minutes.

Meningitis Trust

Fern House, Bath Road, Stroud, Gloucestershire GL5 3TJ

Freephone Helpline: 0808 80 10 388

Phone: 01453 768000

Fax: 01453 768001

Email: info@meningitis-trust.org

www.meningitis-trust.org

The Meningitis Trust is a registered charity that was set up in 1986 by families who had been affected by meningitis. The Trust is committed to increasing understanding of the disease and providing emotional, practical and financial support when it is needed, for as long as it's needed.

The helpline is available in over 100 languages through Language Line and can also be accessed by text relay service.

www.cicsgroup.org.uk

Cochlear implanted children's support group website

www.earfoundation.org.uk

The Ear Foundation offers activities, courses and resources for deaf people who use cochlear implants

www.ci-4teenz.com

A website for teenagers who use cochlear implants

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<http://hearing.screening.nhs.uk/surveillanceguidelines>

MOSAIC, Meningococcal Outcomes Study in Adolescents and In Children. Commissioned by the Meningitis Trust and led by Prof. Russell Viner, UCL Institute of Child Health. Completed Aug 2011, awaiting publication. www.meningitis-trust.org/how-we-help/health-professionals1/research/

NDCS provides the following services through our membership scheme. Registration is simple, fast and free to parents and carers of deaf children and professionals working with them. Contact the Freephone Helpline (see below) or register through www.ndcs.org.uk

- A Freephone Helpline 0808 800 8880 (voice and text) offering clear, balanced information on many issues relating to childhood deafness, including schooling and communication options.
- A range of publications for parents and professionals on areas such as audiology, parenting and financial support.
- A website at www.ndcs.org.uk with regularly updated information on all aspects of childhood deafness and access to all NDCS publications.
- A team of family officers who provide information and local support for families of deaf children across the UK.
- Specialist information, advice and support (including representation at hearings if needed) from one of our appeals advisers in relation to the following types of tribunal appeals: education (including disability discrimination, special educational needs (SEN) and, in Scotland, Additional Support for Learning (ASL)); and benefits.
- An audiologist and technology team to provide information about deafness and equipment that may help deaf children.
- Technology Test Drive – an equipment loan service that enables deaf children to try out equipment at home or school.
- Family weekends and special events for families of deaf children.
- Sports, arts and outdoor activities for deaf children and young people.
- A quarterly magazine and regular email updates.
- An online forum for parents and carers to share their experiences at www.ndcs.org.uk/parentplace.
- A website for deaf children and young people to get information, share their experiences and have fun at www.buzz.org.uk.

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

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www.ndcs.org.uk

Published by the National Deaf Children's Society
15 Dufferin Street, London EC1Y 8UR
© NDCS January 2012 ISBN 978-1-907814-64-8 WEB
Tel: 020 7490 8656 (voice and text) Fax: 020 7251 5020
NDCS is a registered charity in England and Wales no.
1016532 and in Scotland no. SC040779.
This information can be requested in large print, in Braille
and on audio CD.

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