Hearing loss and tinnitus

Meningitis is one of the leading causes of acquired deafness and approximately 8% of survivors will experience some degree of permanent hearing loss[1]. All children should be offered a hearing test within four weeks of being well enough to test after bacterial meningitis and meningococcal septicaemia[2].

This information aims to help you understand the care and treatment that should be provided to children with hearing loss after meningitis. For a more complete understanding of the after effects children can have after meningitis and septicaemia this fact sheet should be read alongside "Your guide". You can record details of your child's illness and recovery, as well follow up appointments, such as hearing testing, in "My Journal".

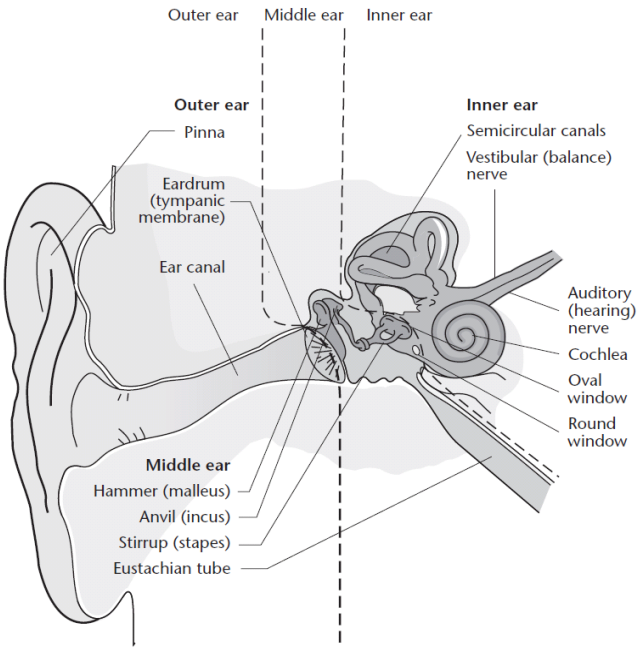

Figure 1: The outer, middle and inner parts of the ear.

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How we hear

Sound is a vibration. Quick vibrations produce high pitched sounds and slow vibrations produce low pitched sounds. Sound entering the ear makes the ear drum vibrate. Vibration of the ear drum moves the parts of the middle ear (hammer, anvil and stirrup), causing a wave to travel through the fluid-filled cochlea.

Fluid moving in the cochlea causes corresponding movement of hair cells, which line the entire length of the cochlea. Movement of the hair cells creates an electrical signal which is sent to the brain via the auditory nerve. Hair cells towards the outside of the cochlea detect high pitched sound while hair cells in the middle of the cochlea detect low pitched sounds.

Numbers within the text that appear as superscripts like this [1] correspond with numbered references listed at the end of this factsheet.

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How hearing is damaged by meningitis

In severe cases of meningitis, bacteria, bacterial toxins, or the chemicals our bodies produce to fight infection may get into the inner ear, where they can cause damage to the hair cells of the cochlea or nerve fibres[3]. Hearing damage from septicaemia is unusual, but can happen if the blood supply to the cochlea or nerve cells is interrupted. Hearing loss from meningitis and septicaemia is described as sensorineural hearing loss and this type of hearing loss is permanent.

If a child has hearing loss after meningitis there is a risk of excess bone growth in the cochlea (called ossification) in the weeks and months after recovery. This can make any existing hearing loss worse and treatment of the hearing loss more difficult or less successful. In children who need cochlear implants ossification can make it more difficult to surgically insert the electrodes into the cochlea. This is one reason why it is so important for children to have their hearing tested, and problems treated as soon as possible after recovering from illness.

Glue ear (caused by fluid in the middle ear as a result of an ear infection) is a common reason for hearing loss in children. Glue ear is extremely common in children under the age of 5 and may not be related to the meningitis at all but can be identified by hearing tests done after meningitis. This condition is not permanent and usually clears up on its own, although it can be longer lasting. Longer lasting problems need to be managed because this can impact on speech and language development and also lead to behavioural problems.

The different types of hearing tests carried out by the audiologist will be able to distinguish what type of hearing loss your child has and whether it is likely to be permanent. It is usually possible for your audiologist to give you the results of your child's hearing test immediately.

Identifying a hearing loss

The type of hearing assessment offered will depend on your child's age and stage of development. For babies and children who are too young to answer questions or respond to behavioural tests, both the Otoacoustic Emission test (OAE) and the Auditory Brainstem Response (ABR) are commonly used. The OAE is part of the standard screening tests all babies have shortly after birth. A small earpiece is placed in the child's ear and a clicking sound is played. If the ear is functioning normally, a faint response will be picked up by the earpiece. In an ABR test an audiologist will place small sensors and a set of headphones

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on the child's head. This test measures whether sound is being sent from the ear, through the auditory nerve to the brain.

Most older children can be assessed with behavioural tests. This is where the child indicates that they hear a sound. If your child has complex needs they may need to be tested using techniques that are normally used with younger children. These techniques often require a child to be asleep so your child may need to have a sedative or anaesthetic before they are tested. If you are concerned that the audiology department you have been referred to does not have the skills to assess your child, you can ask to be referred to a centre with experience of testing children with complex needs. More detailed information on hearing tests is also available from the National Deaf Children's Society (NDCS) website: **http://www.ndcs.org.uk/family_support/understanding_your_childs_hearing_tests/index.html**

Fluctuations in hearing loss have been reported after bacterial meningitis[4-5] and if a hearing loss is identified, you may be offered several appointments to monitor your child's hearing over time. The level of hearing normally stabilises during the first few months following the illness. If you have any concerns about your child's hearing or feel that their hearing has changed since having the initial hearing test, you should ask your audiologist for another appointment, or ask your GP to refer you to the Ear, Nose and Throat (ENT) service.

Levels of hearing

The level of your child's hearing loss indicates which sounds they can hear across the frequency range. Your child may be able to hear certain sound frequencies (or pitches) better than others. Different speech sounds have different frequencies. To be able to hear all the sounds of speech, a range of frequencies must be heard at a low volume.

The loudness of a sound is measured in decibels. The higher the number of decibels, the louder the sound is. Deafness can be described as "mild" (the quietest sounds a child can hear are between 20-40 decibels), "moderate" (the quietest sounds a child can hear are between 41-70 decibels), "severe" (the quietest sounds a child can hear are between 71-95 decibels) and "profound" (child can only hear sounds above 95 decibels). Table 1 provides information about possible outcomes relating to different degrees of hearing loss.

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Table 1: Different degrees of hearing loss and the effect on functional hearing

Level of hearing loss	Functional hearing
Mild (20-40dB)	Children can usually hear everything that is said to them in a quiet room, but not if there is lots of noise present or they are far away from the speaker. The child could not understand a whispered conversation. Some children with mild deafness use hearing aids.
Moderate (41-70dB)	Most children with moderate hearing loss use hearing aids. Without their hearing aids, they could hear most of what someone says to them in a quiet room as long as they speak clearly, but could not follow a conversation in a large group, if there is lots of background noise or they are far away from the speaker.
Severe (71-95dB)	Most children with severe hearing loss use hearing aids and most can follow spoken conversation with one person in a quiet room when using them. Even with hearing aids they may need additional support to understand speech if there is background noise or in groups of people. Without hearing aids they may not hear someone talking to them but might be able to hear louder sounds like dogs barking or drums.
Profound (95dB+)	Most children with profound deafness use either hearing aids or cochlear implants. Without hearing aids or cochlear implants they cannot hear someone talking but may be able to feel very loud sounds like lorries passing in the street. Even with hearing aids or cochlear implants they may need additional support to understand speech in groups or if there is background noise. Some profoundly deaf children use signing as their main means of communication, and many others use signing as a way to support their understanding of spoken communication.

Your child's level of hearing may differ in each ear. Hearing loss in one ear is described as unilateral hearing loss or single-sided deafness (SSD), whereas hearing loss in both ears is described as bilateral hearing loss. The level of hearing loss and frequency of the sounds that are heard can be different in both ears.

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Managing a hearing loss

It is important to identify and manage a hearing loss quickly, especially in young children as the first 3.5 years of a child's life are the most important for developing language skills.

In the UK numerous good practice guidelines and standards have been developed for paediatric audiology services[6-8].

The best way to manage hearing loss depends on the level and type of hearing loss identified. The audiologist will explain the range of options available. If your child has hearing loss, hearing assessments with hearing aids will take place to find out the extent to which hearing aids will help.

The maximum waiting time from referral to treatment in England is 18 weeks[9], Scotland 12 weeks and in Wales and Northern Ireland is 26 weeks. However, The National Deaf Children's Society (NDCS) believes that these waiting times are too long for children to be fitted with hearing aids and would expect hearing aids to be fitted within 2 weeks of diagnosis[10].

Children and young people found to have severe or profound hearing loss should be offered an urgent assessment for cochlear implants as soon as they are fit to undergo testing[2]. They should also be offered an urgent MRI scan to check for possible bone growth (ossification) within the inner ear because this is known to take place after meningitis. This bony growth can make it difficult for a cochlear implant to be surgically inserted into the ear, so it is preferable to undertake cochlear implantation as soon as possible before ossification occurs.

It can be difficult to take in all the information that hearing specialists and other health professionals are trying to relay. Do not be afraid to go back and ask questions when you have had time to think things over. You can use 'My Journal' to list your questions before attending appointments.

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Hearing aids

Hearing aids can be useful for children with hearing loss in one or both ears. They make sounds that enter the ear louder. The hearing aids will be programmed especially to match up with your child's hearing levels at different frequencies. There are many different types of hearing aids and the type provided to your child by the NHS will depend on the type and level of their hearing loss and any specific needs your child has.

Behind-the-ear digital hearing aids are offered as standard on the NHS. There are also hearing aids that work by using vibration called bone conduction hearing aids. Your child's audiologist will provide more information on the most suitable hearing aid for your child.

Any child with hearing loss should be offered regular routine follow up appointments, during which changes in hearing and growth of their ears can be monitored. The hearing aids will need to be adjusted if their hearing changes, and routinely as they grow (e.g. for new earmoulds), so appointments can be as frequent as every 6 weeks in very young children or those with complex needs.

More information about the different types of hearing aids available, their care and maintenance is available from NDCS:
http://www.ndcs.org.uk/family_support/audiology/hearing_aids/hearing_aid_guide.rma

Cochlear Implants

A cochlear implant is different to a hearing aid, instead of amplifying sound it provides a sensation of hearing by directly stimulating the auditory nerves using electrical signals. The implant consists of a receiver which is surgically inserted under the skin behind the ear, an electrode array which is inserted into the cochlea, and a speech processor worn on the ear like a hearing aid. The speech processor passes signals to the internal receiver and electrodes. An implant can provide severe to profoundly deaf children who get little benefit from hearing aids with a sensation of hearing. Implantation in conjunction with auditory support can enable children to achieve age appropriate spoken language. However there are many factors that affect progress and outcomes can be variable for children who have additional problems, such as acquired brain injury (ABI) as a result of the meningitis. More information about ABI after meningitis and septicaemia is available **online** from **www.meningitis.org/recovery** or **www.meningitis-trust.org/recovery**.

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If your child has been found to be severely or profoundly deaf they should be offered an urgent assessment for cochlear implants. In the meantime they should also be fitted with hearing aids because it is important for the ear to remain stimulated. Before your appointment at the cochlear implant centre you should be provided with written information about cochlear implant devices, the assessment procedures and tests[11].

You will usually be referred to your nearest cochlear implant centre for assessment, but as there are relatively few centres across the UK, this may be some distance away from where you live. Here your child will receive a multidisciplinary assessment to determine whether they are suitable for cochlear implantation. This may require several different visits, especially if your child is very young or has additional needs. The assessment process will help you learn more about your child's deafness, measuring both the quietest sounds your child can hear at different frequencies, as well as their functional hearing (ability to understand speech using their hearing aids). Other factors such as fitness for surgery, structure of the cochlea, the presence of a functioning auditory nerve and the likely ability of the child to benefit from the cochlear implant system[12] will all be taken into consideration.

You may be worried about the suitability of cochlear implants and want to be sure that a cochlear implant is right for your child. The assessment procedure is very detailed and there will be plenty of opportunity to discuss any concerns you have with the relevant specialists who should keep you updated throughout the process. At the end of the assessment you will be invited to discuss the results with the cochlear implant team and jointly make a decision about whether your child should have cochlear implants. Although you should not be rushed into making a decision, assessment should take place quickly. It is recommended that children opting for cochlear implantation have implants fitted in both ears at the same time[12]. This is especially important for children who have recovered from meningitis because ossification (which usually happens in both ears) can reduce the success of cochlear implantation at a later date.

There is evidence to suggest a small increase in risk of contracting pneumococcal meningitis following cochlear implantation[13], although another study found no increased risk following implantation in children[14]. To manage this risk, all children should be up to date with their routine immunisations and children over the age of 2 should have an additional pneumococcal vaccination. You should try to get your child vaccinated before surgery, but as it is important not to delay implantation, this can be given afterwards.

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NDCS has an award winning resource about cochlear implants which is available from:
http://www.ndcs.org.uk/family_support/audiology/cochlear_implants/cochlear_implants.rma

The Ear Foundation has an online tutorial which is available from:
http://www.earfoundation.org.uk/education-programme/education-online/overview-of-cochlear-implants

Support following cochlear implantation

Children who have cochlear implants are supported by a team of professionals including Teachers of the Deaf, Speech and Language Therapists, Auditory Verbal Therapists, Hearing Therapists and Audiological Scientists. Cochlear Implants need to be set up to individual requirements and this is done by Audiological Scientists in a process called programming. Programming ensures that the cochlear implant user can hear sounds across a comfortable range from quiet to loud.

The sound provided by a Cochlear Implant is different to that given by normal hearing. The time is takes for people to make sense of this sound varies and we call this period 'learning to listen'. The model of support varies between Cochlear Implant programmes but all provide education and therapy to enable Cochlear Implant users to reach their potential for listening.

Other Equipment

It is important to make the home and school environment as practical and accessible for your child as possible. Equipment is available to help promote your child's independence. Some of this equipment can be provided to you by local education or social care services, but some may need to be purchased independently. Equipment can help with:

Alerting – These use flashing lights or vibration to signal that something is happening such as the phone/doorbell/fire alarm ringing

Communication – Including Text phones, amplified and hearing aid compatible telephones and videophones.

Listening – There are various listening devices available which work with your child's hearing aids or cochlear implants to help them listen to a particular sound source and cut out background noise or interference. Some examples of listening devices are:

- Radio aids, which can be worn by a child and teacher in the classroom so that the

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child can hear the teacher's voice at a consistent level even when the teacher is at the other end of the room and there is background noise

- Loop systems can be installed at home and are often found in public places such as cinemas. People wearing hearing instruments can 'plug in' to hear the source of the sound, limiting background noise
- Personal listening aids and infrared listening aids can be used to listen to a chosen sound source by placing the microphone close to the source of the sound i.e. television, person or radio

Entertainment – Various devices can give deaf children access to equipment like MP3 players, computers and televisions which is important for their social well-being and education.

The NDCS Technology at home booklet provides detailed information about the sort of equipment available for deaf children and detailed advice on how to access such equipment from social services or your local authority. The booklet can be downloaded from **http://www.ndcs.org.uk/family_support/technology/index.html**

Communication

Good communication skills are vital to enable children to learn from others and interact with the world. There is no single best way to communicate with your deaf child. In fact some approaches work well in some circumstances but not so well in others. There are three main communication approaches:

Auditory-oral – hearing technology is used to develop listening and speaking skills

Sign Supported English – signs are used alongside spoken English as a way of making English more accessible

Sign bilingualism – Sign Language (such as British Sign Language) and English are used. Sign language is used without spoken words and has a different word order and grammar from spoken language. In sign bilingual settings children are often exposed to British Sign Language and Sign Supported English.

Total communication – When a variety of methods of communication are used in a combination that works best for the deaf child. Methods include signing, gesture, symbols,

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speech, hearing, finger spelling, lip-reading and facial expressions.

Support for all communication choices isn't always available everywhere. If you find that your child's chosen method of communication is not supported by local services in your area then talk to your local practitioners such as your child's teacher of the deaf or audiologist to help get access to the information or support that you need.

If your child has multiple disabilities they may be unable to communicate using many of the methods already discussed, but there are other ways that your child may be able to communicate. More information about communication is available from NDCS's "Communicating with your deaf child" available from **http://www.ndcs.org.uk/family_support/communication/communicating_with_your_deaf_child/index.html**

Tinnitus

Tinnitus has been identified as a possible after effect of meningitis[15-16]. Tinnitus is a general term that means any sound that is heard in the ears or head that hasn't come from an external source, for example a ringing or buzzing noise in the ears. The majority of people have experienced tinnitus at some time, for example noticing a ringing in the ears after a gig or night out at a club. It can affect those who have it in very different ways, from being a trivial complaint to a debilitating condition. Disrupted sleep is one of the most significant complaints amongst tinnitus patients with approximately 80% of children with tinnitus reporting sleeping difficulties. Many patients also report that tinnitus can affect their attention and concentration[17].

If your child is old enough to describe hearing sounds in their ears, especially if they are worried or upset by them, you can seek medical help. If your child is experiencing tinnitus alongside a hearing loss you should discuss this with your audiologist or, if you have one, ENT consultant/otologist or audiovestibular physician. If your child has no underlying hearing loss, but is experiencing ringing in the ears you should discuss this with your GP who can refer your child to one of these specialists. It may not be possible to "cure" the tinnitus, but there are various techniques that can be used to reduce the impact.

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Balance problems

Children who have been deafened by meningitis are at a relatively high risk of balance problems. In fact, one research study found that over one third of children who had permanent hearing loss as a result of meningitis also had problems with balance[18].
A factsheet on balance problems is available from
http://www.ndcs.org.uk/family_support/audiology/balance_and_balance.html

Education and learning

All babies and children diagnosed with a permanent hearing loss should be referred to a hearing support service (also known as sensory support service) provided by the local education authority because they may need skilled support to develop language and communication skills and to help them achieve their potential at school. Children are usually referred by their paediatrician, GP or audiologist but you can refer your own child for such services by contacting the relevant department of your local authority.

The sensory support service has a team of teachers of the deaf who can work with you and your child before school and throughout their school years providing practical advice on all aspects of language and communication. They can offer the following:

- advice to help you make your choice of schools when your child is due to start
- advice about which communication approaches to use with your child
- information and advice on the level of support your child will need at school
- advice to the school about how to work best with your child
- information about the range of specialist equipment available to help your child.
- direct and indirect work with your child (support before your child attends school, support in class, training to school staff etc.)

Meningitis can be associated with more subtle after effects and a proportion of children who survive have difficulties with concentration, learning and memory as well as with aspects of behaviour. If you are concerned about any aspect of your child's learning or behaviour, it is really important to speak to their teachers and raise your concerns. You may find it helpful to discuss any concerns with your child's teacher of the deaf. It would be a good idea to take along a copy of "Your guide" and "My Journal" for your child's teacher to read and to

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help explain your concerns.

NDCS have put together a useful online programme to help deaf children with their working memory. This is available at **http://www.ndcs.org.uk/workingmemory/index.html.**

Factsheets about behavioural, emotional, memory, concentration and learning problems following bacterial meningitis and septicaemia are available online.

www.meningitis.org/recovery

www.meningitis-trust.org/recovery

Financial support

You may be entitled to claim benefits as a carer of a deaf child. The main benefit is Disability Living Allowance (DLA). This is available to children up to the age of 16. Additionally, if your child is awarded DLA you may be entitled to receive a carer allowance.

Detailed information about how to claim benefits for your deaf child can be found at **www.ndcs.org.uk.**

People you may meet

Audiologist/audiological scientist - Audiologists assess, diagnose and manage patients who have hearing, balance and tinnitus problems. They will carry out tests on your child and explain the results to you. If your child needs hearing aids, they will work out the most appropriate type and monitor your child's hearing to ensure the hearing aids remain appropriate.

Audiological physician (or audiovestibular physician) - A consultant doctor specialising in the investigation, diagnosis and treatment of hearing and balance problems.

LSLS Certified Auditory Verbal Professional - This is someone who has trained as an Audiologist, Speech and Language Therapist or Teacher and will have completed additional training. They will focus on developing spoken language through listening and most often through individualised therapy sessions.

Community paediatrician in audiology - A medical doctor specialising in children's health with a specialist interest in hearing problems.

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ENT (ear, nose and throat) surgeon/Otolaryngologist - A medical doctor trained to diagnose and treat diseases of the ears, sinuses, mouth, throat, larynx and other parts of the head and neck. An ENT surgeon will perform cochlear implant operations.

Speech and language therapist - The role of a speech and language therapist (SLT) is to assess and treat speech, language and communication problems in people of all ages to enable them to communicate to the best of their ability[19]. SLT's often work closely with the Teacher of the Deaf.

Clinical psychologist - A clinical psychologist will consider the learning, social and emotional needs of a child with hearing loss. The role of the psychologist may be to help a child wear hearing aids, help them cope with medical procedures (such as cochlear implant operations), and to support parents following their child's hearing loss.

Teacher of the deaf - Teachers of the deaf may work for the local education authority and support deaf children who are integrated into mainstream and special schools on an individual basis. An important part of their work is collaboration with mainstream classroom teachers who teach deaf pupils from day to day, and the management of support provided by teaching assistants (TAs) or Communication Support Workers (CSWs) who often accompany deaf pupils in lessons. Teachers may also visit parents of very young children at home to advise about the child's development and to work with them as appropriate. They can also support deaf children with other disabilities or older children moving to further/higher education.

Teachers of the Deaf also work as part of a team in hospitals/health centres, concentrating on audiological and advisory services, particularly in the early years. They often work closely with the SLT.

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Further sources of information and support

A wide range of information and support is available to both children who have become deaf, and parents of children deafened by meningitis. Support can come from a variety of places such as local deaf children's societies, services for deaf children, voluntary organisations or other parents of deaf children. Some useful organisations to contact are listed below:

Action on Hearing Loss

A charity providing support for people with hearing loss and tinnitus

Website: www.actiononhearingloss.org.uk

Freephone Helpline: 0808 808 0123

Textphone: 0808 808 9000

Auditory Verbal[UK]

National charity which teaches deaf babies and children to listen and speak using Auditory Verbal Therapy, so that they can achieve their potential in life

Website: www.avuk.org

Email: info@avuk.org

Tel: 01869 321492

British Tinnitus Association (BTA)

The BTA strives to be the primary source of support and information for people with tinnitus and their carers in the UK and to advocate on their behalf.

Website: www.tinnitus.org.uk

Email: info@tinnitus.org.uk

Freephone Helpline: 0800 018 0527

CICS – Cochlear Implanted Children's Support Group

Founded by parents whose deaf children use cochlear implants. The group help others with children who already have implants and those who are considering cochlear implantation.

Website: www.cicsgroup.org.uk

Email: info@cicsgroup.org.uk

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National Deaf Children's Society (NDCS)

A charity dedicated to creating a world without barriers for deaf children and young people. NDCS uses the term deaf to mean all types and levels of hearing loss.

Website: www.ndcs.org.uk

Email: helpline@ndcs.org.uk

Freephone Helpline: 0808 800 8880

The Ear Foundation

The Ear Foundation work to bridge the gap between hospital specialists and families of children and young people who use hearing technology.

Website: www.earfoundation.org.uk

Email: info@earfoundation.org.uk

Tel: 0115 942 1985

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