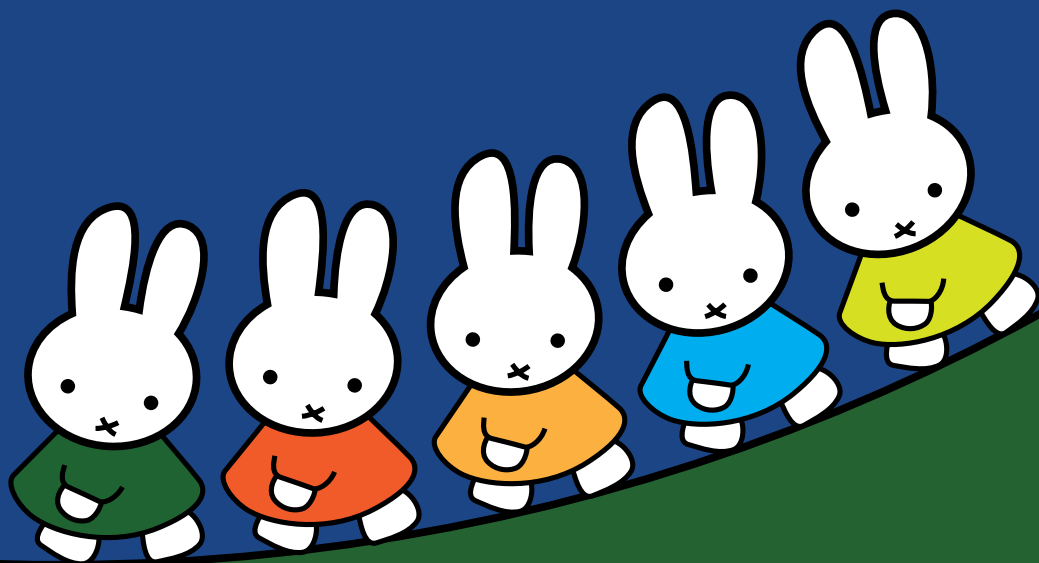


Welcome to Miffy Transitional Care Unit



This leaflet explains about the facilities available on the Miffy Transitional Care Unit and what to expect when your child stays with us.

Information for young people and families

Great Ormond Street Hospital for Children NHS Trust

What is the Miffy Transitional Care Unit (TCU)?

The unit is for children who require long-term respiratory support and care. Children staying on the unit are usually 'in transition' between needing hospital treatment and needing care in their own home. The ultimate aim of the unit is for you and your child to be able to go home feeling confident about his or her care with appropriate professional help and support.

While children stay with us, our aim is to help them achieve their full potential, whether medically, developmentally or emotionally. We hope to achieve this by working closely with you and your child, and offering an environment in which all family members feel welcome and involved.

We aim to make the unit as near to normal life as is possible within a hospital, and hope that it will be enjoyable for you and your child.

How is Miffy TCU different to other wards?

Miffy TCU is different because your child's care needs have changed and he or she now needs a different environment. Your child may have had lots of technical or acute medical interventions before coming to us. However, now that he or she is medically stable, the emphasis of care can change. The focus can move on to both your child's developmental needs and helping you to develop your skills and confidence in caring for your child in hospital and at home.

You will find that it is possible for you to be involved in your child's day-to-day care and decisions about routine. We aim to encourage parents to be as fully involved in all aspects of care and planning as possible.

Miffy TCU is a small ward consisting of five bedrooms. There is a daily ward round, led by the respiratory doctor.

It is likely that some aspects of your child's respiratory care will be different from other wards. The nurses will discuss the reasons for this with you, but please ask us if you are unsure about anything.

Will I be trained to take care of my child's tracheostomy and ventilator?

We will give you a ward-based competency book to complete, which covers all aspects of your child's care. Once you have completed the book and you feel confident, you will be able to take your child away from the unit without a member of staff.

Meet the multiprofessional team

Staff that provide day-to-day care on the ward are a mixture of qualified nurses and student nurses. In addition, there are other people who will be involved in caring for your child and family, such as:

- Consultant respiratory doctor and specialist registrar
- Dietitian
- Family psychotherapist
- Multi-faith chaplaincy team
- Music therapist
- Occupational therapist
- Play specialist
- Physiotherapist
- Schoolteacher
- Social worker
- Speech and language therapist

More information about the team follows.

Nurses and carers

■ Sister

The ward sister leads a team of qualified and experienced nurses and carers on the ward. She has a significant role, together with the multiprofessional team, in the process of discharging your child home to the community.

■ 'Named nurse'

A 'named nurse' is the member of staff responsible for your child's care, coordinating what is needed and representing your child's interests as necessary. He or she will also teach you the skills you need to care for your child, help you plan for going home and liaise with other members of the team. Your 'named nurse' is your key point of contact during your child's stay with us.

■ Doctors

All patients on Miffy TCU are under the care of a named consultant in respiratory medicine. Day-to-day supervision is carried out by one of the

specialist registrars on the ward. There are regular ward rounds, when each child's medical, nursing, psychosocial and rehabilitation needs are reviewed in detail.

■ Psychosocial team

We know that a child's illness or condition can affect the whole family. Coping with illness, the impact of a long-term stay in hospital and transition to home care can be very stressful for everyone. Practical and/or emotional problems can develop, and the psychosocial team can help you deal with these worries and concerns. The psychosocial team consists of a social worker and family psychotherapist, who may work with you individually or together.

Social worker

The social worker for Miffy TCU can offer practical and emotional support to you while your child is staying on the ward. We recognise the pressure on parents, brothers and sisters,

particularly when your family may be temporarily split between home and hospital. The social worker is also involved in planning your return home attending the weekly ward rounds and with your permission, contacting various local services.

We will contact the 'children with special needs team' in your own local social services to ensure that you get all the help you need when you take your child home. If your house or flat presents problems for returning home, we will also contact your local housing department or association. We sometimes speak to your local education department so that they understand your child's needs for school or nursery.

We can offer a small amount of financial help towards the extra cost of both staying at the hospital and travelling to and from home. We can also advise about benefits and charities that may be able to help financially.

See the *Useful contacts* list at the end of this leaflet for further details.

Family therapist

The aim of family therapy is to help you use your family strengths to overcome any difficulties that you may face and to offer a space and time for reflection. Children can be helped to express their feelings through talking or play. The family therapist can work with you, your child and brothers and sisters in different combinations as appropriate. Talking to the family therapist may also help you to think ahead about the family adjustments that often take place when a child goes home with a care team.

■ Multi-faith chaplaincy team

The multi-faith chaplaincy team visit the ward regularly to listen confidentially and reflect with you, whether or not you are religious. We are interested in your life journey and want to support you and your child by our presence and prayers during

your stay. There is a chaplain on call 24 hours a day, so please ask a member of ward staff to contact us.

■ **Therapy team**

The therapy team aims to enable your child to reach their full potential using team members' different specialist areas. They will assess your child, and design a therapy programme with you that is tailored to your child's needs. Where possible, this can be incorporated into your child and family's daily routine and play. The therapy team may involve your child in group sessions with other children on the ward and/or may work with you individually. They can also offer training to ward and community carers if appropriate.

Occupational therapy

The occupational therapist will assess and treat your child in a number of areas, including self-care, classroom skills, and play activities. All these work on improving your child's visual and perceptual skills, sensory

difficulties, motor coordination and psychosocial skills. He or she is also involved with improve your child's access to his or her environment at school and home. They are involved in planning your child's discharge, assessing your child for any adaptive equipment, including home adaptations and seating or wheelchair needs.

Physiotherapy

The physiotherapist will be involved with your child if he or she has delays in physical development or problems with motor skills. If your child has weakness or stiffness in his or her limbs or trunk, the physiotherapist can be involved in postural management, which may include stretches and positioning, or special equipment such as standing frames and supportive chairs. This ensures that your child's hips and spine develop correctly. Your child may also need chest physiotherapy, if he or she has breathing problems, using positioning or other techniques to improve breathing.

Speech and language therapy

The speech and language therapist will work with your child if he or she has communication or feeding difficulties. They can also offer specific feeding programmes. One of the aims of the speech and language therapist is to help your child communicate as effectively as possible with you, your family and staff members. Where possible, these strategies will be incorporated into your daily routine. Alternative or additional communication may be used to help your child understand his or her environment, and opportunities for communication using, for example, photographs, symbols or Makaton signing. Speaking valves for your child's tracheostomy can be introduced as appropriate.

Dietitian

The dietitian's role is to ensure that your child's nutritional requirements are met to support growth and development. We

can advise on diet for different forms of feeding, such as oral or tube feeding. We can also offer advice on weaning your child onto solids.

Play worker

The unit has a part-time play worker. Their role is to develop play programmes that stimulate and help with your child's all-round development as well as providing a distraction and normality to your child's day. This may also be available for their brothers and sisters. The play worker is also on hand to help prepare your child for any procedures or treatments they may have during a stay. This might involve direct work with your child and/or helping you as parents to prepare your child in an age appropriate way.

■ Schoolteachers

The Children's School is on level 2 of the Southwood Building and is open daily during term-time, including half terms. The school aims to provide enjoyment, normality and

continuity of education and to aid the recovery process. Miffy TCU has a named schoolteacher who contacts the ward regularly to answer questions or discuss individual needs. Where possible, pupils are encouraged to attend the wide range of timetabled lessons in the schoolroom, but where this is not possible, a teacher may be able to work with a child or small group on the ward for around an hour each day. Further information is on the school notice board on the ward or by phoning extension 8269.

How will staff work with my child and family?

We hold review meetings about your child every four to six weeks. These meetings usually involve all the professionals working with your family. Initially, this will only be staff from the ward, but over time, professionals from your local area will also be involved to ensure as smooth a transition as possible when you return home.

The review meeting is another opportunity for you to hear from the professionals about their views on your child's progress and for you to share your views and concerns. We also make plans for your child's care until the next review meeting.

What can I expect from ward staff?

You can expect us to provide the best possible care for your child and all the members of your family. We will endeavour to treat your child and members of your family fairly and with dignity and respect. We will also work hard to provide a trusting and caring environment, in which both professionals and families can work together in partnership.

What will ward staff expect from me?

We will encourage you to take part in all aspects of your child's care, as much as you feel able. We will encourage and support you in learning to care for your child.

Comments and complaints

We know that there may be times when family members can feel angry, frustrated or upset and we hope you will feel able to express any concerns or worries to the appropriate staff. However, if you feel that the matter is not resolved, you can speak to a manager or head of department. The hospital has adopted a 'zero tolerance' approach to behaviour that is inappropriate or threatening to patients or staff.

The Pals office is on level 2 of the hospital, opposite the shop. The Pals team is there to support you in making any concerns heard. They can liaise with staff to sort out problems or provide information. They are open from 9am to 5pm Monday to Friday and from 10am to 12pm on Saturday. You can ring them on extension 7862 or email them at pals@gosh.nhs.uk.

Should you wish to make a formal complaint, the following procedures apply:

- For NHS staff and services, you can write to the Complaints Manager at GOSH. More information about the complaints process is in our leaflet *How to make a complaint*, which is available in various places around the hospital.
- For social services, you can contact Camden Social Services by ringing their freephone number 0800 303 561.

If you require an interpreter or advocate to assist with this process, please ask a member of staff to arrange this.

Useful websites and contacts for TCU families

Aid for Children with Tracheostomies – ACT

Provides regular newsletter, support and advice, local support groups, equipment hire and a holiday caravan.

Tel: 01823 698398

Website: www.actfortrachykids.com

Breathe on UK

National children's charity that provides ongoing support to children on long-term ventilation, their families, medical centres and care staff.

Tel: 01258 820 951

Website: www.breatheon.org.uk

Long-term ventilation

Information for parents and healthcare professionals involved in the care of children who need long term ventilation

Website: www.longtermventilation.nhs.uk

Disabled Facilities Grant

Government funded grant to allow adaptations and extensions to your home to accommodate a disabled or technology-dependant child.

Not means tested. Information is on the Directgov website at www.direct.gov.uk if you search for 'disabled facilities grant'.

Notes

**If you have any questions,
please telephone the Miffy Transitional Care Unit on 020 7813 8339.**

© GOSH Trust December 2010

Ref: 2010C0125

Compiled by the Miffy
transitional Care Unit in
collaboration with the Child and
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www.goshfamilies.nhs.uk

www.childrenfirst.nhs.uk

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Great Ormond Street Hospital for Children NHS Trust