



Royal College  
of Nursing

# Children and young people with diabetes

*RCN guidance for newly-appointed nurse specialists*





## Acknowledgements

The Royal College of Nursing would like to thank the following for their contribution in updating this version of the publication:

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Amanda Mackin, Children's Diabetes Nurse Specialist, Leighton Hospital, Crewe

Grace Parfitt, Children's Diabetes Nurse Specialist, Royal Gwent Hospital, Wales

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This publication is due for review in November 2015. To provide feedback on its contents or on your experience of using the publication, please email [publications.feedback@rcn.org.uk](mailto:publications.feedback@rcn.org.uk)

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Published by the Royal College of Nursing, 20 Cavendish Square, London, W1G 0RN

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## RCN guidance for newly-appointed nurse specialists

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# Foreword

Specialist diabetes nurses play a key role in supporting children, young people and their families. Numerous research studies and audits demonstrate the significant impact they can have in achieving good diabetic control and overall management. Parents, children and young people rely on their support, advice and guidance.

Some specialist nurses however work in isolation. This guidance will sign post those new to a specialist nurse role to resources and sources of support. It also highlights issues that need to be considered by the individual as well as their employing organisation.

## 1

## Introduction

The Royal College of Nursing's Paediatric and Adolescent Diabetes Group (RCN PADG) first produced guidance for newly-appointed paediatric diabetes specialist nurses (PDSNs) in 1997. The RCN Children and Young People Diabetes Community (CYPDC) has now updated the document twice to help specialist nurses to further improve the quality of service they provide for children, young people and their families. Guidance is provided about setting up and managing a service, keeping yourself and the child or young person you work with safe, working with other members of the multidisciplinary team (MDT) and maintaining your personal and professional development.

### Philosophy

Children and young people have rights in both the family and wider society. They should remain at the centre and key focus for all decisions regarding their diabetes care and it is paramount that specialist nurses recognise this. The nurse's focus is to assist children and young people and their families to manage the physiological, physical, social, psychological and spiritual effects of type 1 diabetes (RCN, 2003).

## 2

## Setting up the service

When you set up a service it is important to consider ways in which you can establish yourself in the MDT and with other health professionals. This includes, for example: general practitioners; community children's nursing teams; health visitors; local hospitals; social services; local children's units; and anyone else who you may come into contact with. Excellent communication skills will facilitate consistency and team targets, which are recognised as key attributes in the most effective teams. Recognising the skills and expertise of other team members will also facilitate smooth integration and collaborative working in the interdisciplinary team.

### Boundaries for practice

Identify your organisation's policies, protocols and guidelines that underpin practice as well as national drivers – for example the Best Practice Tariff (BPT). These should cover all aspects of your role, and must be agreed and signed by both your manager and the paediatric consultant(s) with whom you are working. Identify your organisation's protocols for:

- treatment of children newly diagnosed with diabetes
- management of diabetic ketoacidosis
- management of children having surgery (planned/emergency)
- sick day rules
- management of hypoglycaemia
- insulin pump therapy
- schools, diabetes awareness sessions, blood glucose, ketone monitoring and insulin administration
- non-medical prescribing
- inpatient management
- lone working
- safeguarding children and young people and the referral processes.

## 3

## Managing your work

Ensure that all policies, protocols and guidelines are evidence-based and in line with the National Service Frameworks for children and diabetes. They should also conform with the National Institute for Health and Clinical Excellence (NICE), British Society for Paediatric Endocrinology and Diabetes (BSPED), Scottish Intercollegiate Guidelines Network (SIGN) and International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines.

### Support network

If you are the only nurse in the children's diabetes team then consider who you can go to for support, training and clinical supervision. Establish links with other teams such as the community children's nursing and adult diabetes nursing teams, as well as other children's diabetes specialist nurses (CDSN) working in the area. Why not consider spending time shadowing another CDSN in their work?

Keeping other team members up to date with your activities and any challenging issues through regular meetings can also ensure effective team working and support.

Joining your regional clinical network is another way to initiate links with professionals, and keep up with the latest changes in commissioning children's diabetes services and diabetes research. If it's difficult to attend the meetings – just ask to be added to the mailing list to receive the minutes.

Create your own professional support network. Send out a standard letter introducing yourself to all children and young people and their families on your caseload and include inpatient and community-based colleagues, with your contact details and working hours. Providing this information ensures that they know who they can contact to access support and advice.

Caseload planning and liaison are critical when organising your daily schedule. This is what you should consider:

- ensure you plan carefully and clearly in your diary – someone might need to take over at any time, for example, if you are ill they will need to be able to see your work plan and patient records easily
- schedule in your diary any regular meetings, clinics and training sessions including mandatory training and safeguarding updates
- liaise with the clinical area about inpatient activity that requires your attention
- follow your organisation's lone worker policy when you arrange and conduct home visits
- do not overbook patient contacts – allow adequate time for travelling between home visits
- leave time after each visit for recording your consultations, checking message books or the answer phone and returning calls
- anticipate that plans may need to change at short notice for emergency calls or newly-diagnosed children and young people and their families
- any social activities with your client group are part of your job description and should be included in your work hours
- age-appropriate social activities with children and young people can be an important area to be included as this can build self efficacy which can effect diabetes management
- taking a lunch break is a legal necessity, and should be scheduled in your diary.

### Accessibility

When you are away from the office you need to establish an efficient way for people to contact you. It is important that you carry a mobile phone with you at all times, and that it is used appropriately in line with your organisation's policy. This will keep communication links open while you are away from the office. Ensure the answer phone message

## 4

## Newly-diagnosed children and young people and families

clearly states your availability and alternative contact details where children and young people and their families can get support if you are not available.

When you use an office-based answer phone make sure that any messages you leave are clear and concise. The message should explain to children and young people and their families how to access emergency help, and how often you are likely to listen to messages (remind callers it could be the following day before you pick up messages). Ensure messages are cleared frequently and documented accurately.

Another way to communicate efficiently with your clients and their families is via text messaging and a secure email server. Discuss this with your organisation's IT department. It is vital you are aware of, and use, your organisation's information governance protocols. This will ensure the necessary safeguards are in place for the appropriate use of patient and personal information.

If you share 24-hour responsibility for out-of-hours with ward staff or junior medical staff, make sure that robust guidance is in place for managing common situations in your absence. Care pathways and flowcharts for escalating advice can also support out of hours advice. Smart phones can improve flexibility of accessibility further and ensure a rapid response to children, young people and their families. Smart phones will allow ease of access to and liaison with other professionals. Do not give your home number to colleagues, children and young people and their families.

If the budget allows, get a business card printed with all your contact information.

### Record keeping

All written or computerised records, including your diary, are legal documents and must be kept safe. Remember to maintain patient confidentiality in the way they are stored. Record keeping must meet local policy and current Nursing and Midwifery Council guidelines (NMC, 2009). There are a number of things to consider. For example:

- in what form will you keep patient records?
- how will you keep records safe when travelling and visiting children and young people and their families?
- how will you record communication with members of the multi-disciplinary team and messages left for you?
- how will you keep messages confidential?

A good start at diagnosis which is maintained during the first year is important in building self efficacy and empowerment. Consultation skills, which help build collaboration and rapport with the MDT particularly around breaking news of the diagnosis, facilitate this process. A pathway or flowchart can help to illustrate diabetes management and education for children, young people and their families. This will ensure they are given all necessary information about diabetes, and records what information they have had.

It is important to ensure staff on the children's ward are also part of, and familiar with, this pathway so that once a child/young person and the family have been given a diabetes diagnosis they can begin a programme of diabetes education which can be followed seven days a week, 24 hours a day.

Inpatient staff should also be informed regarding inpatient care standards and recommendations through regular contact and more formally through a rolling programme of education and study days. Education is believed to be key to the successful management of diabetes in young people (Swift, 2007; ISPAD, 2009). Develop an educational package on the different aspects of diabetes care that can be used in initial and ongoing therapy. If you use pre-prepared information, ensure it complies with your team's philosophy of care and best international evidence-based guidelines. Encourage the family to join Diabetes UK and the Juvenile Diabetes Research Foundation (JDRF), which provide special services and groups for children of different ages. See the appendix for contact information.

## 5

## Discharge plan

Hospital discharge planning starts at the time of admission. Close collaboration with the MDT, primary care staff, education authority or schools is key at diagnosis and for ongoing care. This should be fully discussed with the child and family prior to discharge. Where possible, consider using the local community children's nursing team services to support your client and their family during the initial period after discharge.

## Consultations

The main purpose of the consultation should always be considered as this will influence whether a home visit, nurse-led clinic appointment, medical appointment, group education session, telephone, text or email is the most appropriate.

Additional considerations include whether any resources such as space, access to a computer, equipment (HbA1c analysers, CGM sensors, meters, pens, ketone strips etc), educational leaflets or documentation (for example school care plans) are required.

## Maintaining a professional appearance

Not all children's diabetes specialist nurses wear a uniform, some wear uniforms while in the ward environment and clinic but not in the patient's home. Regardless, a professional image is essential at all times, both in your dress and overall appearance. Remember, you are on duty even when you are driving in your car. Your manager can advise you on whether an allowance is available to help you buy appropriate extra non-uniform clothes.

## 6

## Home visits

### Conducting home visits

Home visits can offer a unique insight into potential challenges which may impact on diabetes. The home environment may also facilitate an environment where child/young person and their families feel able to disclose their worries and concerns.

You must apply your organisation's lone worker policy when you make home visits. When you visit, you are a guest in your client's home and have no legal right to be there. Respect their home, and act as a guest. If you want to take someone with you such as a student, then ask permission from the child/young person and family in advance. Give the family an idea of how long your visit will take. This removes the possibility of embarrassment on either side, and the visit can be terminated when the time allowed has elapsed. Try to be punctual. If you are running late, phone to let the family know as soon as you can.

### Personal safety

Most homes and families are welcoming, but if you are visiting a client who you feel uneasy with or who lives in a high-risk area, undertake a risk assessment. You could consider taking a colleague with you, or use other methods of contact and support such as a nurse-led clinic that children and young people and their families can access. Be guided by your organisation's lone worker policy. The Suzy Lamplugh Trust is a good source of information on working methods: [www.suzylamplugh.org](http://www.suzylamplugh.org)

Always carry a personal alarm, mobile phone and torch. If the visit is scheduled at night, park your car in a well-lit area. When you are in a client's home where you feel uneasy, always keep yourself between the family and the door, so you have a clear exit if required. If you feel unsafe during the visit, terminate the visit and leave. If the family have pets that you feel uncomfortable around, ask the family to put them in another room until you leave.

## Travelling

### Car insurance

If you use your own car for work you must inform your insurance company, or your insurance may be invalid. This usually has no extra cost.

### Lease car

If you have a lease car, your liability for tax will change. Make sure you are aware of how this works, or you may face an unexpectedly large tax bill at the year end – your employer's pay and staff services department should be able to supply you with more information about this. Lease cars generally mean you pay a higher level of tax. However, you can reduce this through voluntary contributions towards the cost of the car, using a car that is more environmentally friendly, and minimising the amount of private miles that you drive.

### Mileage

Develop a regular recording system for your mileage claims, both personal and business. For example, you should record mileage in a separate book or in your work diary. Your manager and organisation's human resources department will explain the process for completing and submitting expenses claim forms. It is important that you discuss travel allowances with your manager to make sure that you are recorded on the correct beneficial-user scheme for your particular post.

### Safety

It may be beneficial to buy a satellite navigation system or street maps of all the areas you are likely to cover. Make certain that you have your child/young person's and their family's contact numbers with you at all times, and work out travel directions before you leave base. When you make home visits remember to store all the documentation and medical equipment that you need out of sight in your car boot. You should be a member of a car recovery scheme to help you if you break down or have an accident.

## 7

## Children and young people's diabetes clinics

Many studies demonstrate a team approach to diabetes care improves health outcomes (NICE, 2004, Craig and Glastras et al., 2007, ISPAD, 2009). There should be a named consultant(s) with a special interest in childhood diabetes, children's diabetes specialist nurse and a paediatric dietician at your paediatric diabetes clinic. Other members of the MDT may also be present. Share information with other team members before and after clinics, at a weekly meeting or document in a jointly agreed location.

Intermittent review of the flow through the clinic, structure, team targets and philosophy as well as feedback from children, young people and families can also improve efficiency and effectiveness.

Tailoring clinic consultations to the age of the young person to maximise engagement and self management in an age appropriate manner can also add value. Access to a play specialist or youth worker to fully utilise waiting times are also worth considering. Planning transition in advance will facilitate a smooth transfer to adult services, and reduce the risk of losing young people to follow up (NICE, 2004; RCN, 2008; and Viner, 2008). A minimum of four appointments a year should be offered to all children and young people. If they do not attend, contact should be sought by the children's diabetes specialist nurse.

Information that is available in clinics should be appropriate to the age of the child or young person. It is advisable to keep a record of exactly what literature you give each client. Several companies with diabetes-related products also supply information leaflets covering a wide range of topics, and these can be useful resources at clinics.

You might find it useful to visit other local teams with a similar population to observe the structure and function of their clinics.

### Nurse-led clinics

Nurse-led clinics can be an efficient use of time. They can be based either in the hospital or in the community, depending on the availability of resources and the needs of the local community. Nurse-led clinics can provide, for example:

- an educational opportunity for children and young people
- provision of psychological support
- a review of the child/young person's current glycaemic control and insulin adjustment if indicated
- a change of insulin regimen
- demonstration, insertion of sensor and download, and analysis of new technologies.

Nurse-led clinics should be structured and planned according to the specific requirements of your caseload. It may be worth investigating other nurse-led clinics in your area, and ask if you can attend in order to review how they work and how the activity is recorded.

## 8

## Educational role

Initial and ongoing structured education for children and young people and their families is integral to the care you provide. Every child or young person with diabetes is entitled to education to support them to manage their diabetes (Swift, 2007, Swift 2009). Education should be structured, planned and evaluated (DH, 2005b). You can access guidelines to help you via the NHS paediatric diabetes website at [www.nhs.uk](http://www.nhs.uk)

There are a variety of educational tools to meet a range of different learning styles such as e-learning, websites, computer games and group sessions. To ensure the best quality of care is provided to children and young people and their families you should also provide education in the wider community and for fellow professionals using best practice guidelines.

### Hospital staff

Ensure that policies, procedures and guidelines are up-to-date and available for all hospital staff who are caring for children and young people with diabetes. These guidelines should include:

- managing diabetic ketoacidosis (DKA)
- nursing care plans for DKA
- children and young people with diabetes undergoing a surgical procedure
- guidelines for capillary blood glucose testing and ketone monitoring
- insulin injections
- pump therapy.

Hospital staff will require regular updates and training in the use of all diabetes equipment such as blood glucose and ketone monitors and insulin pens. The Medical Devices Agency guidelines (2002) require training to be provided using a competency-based system. All staff should complete an e-learning package on the safe use of insulin (Healthcare e-Academy, NHS, 2010). Support to undertake this training can be provided by companies that supply the blood glucose monitors and pens, as well as from your organisation's education and training department.

To offer 24-hour support to children and young people and families it is important to work collaboratively with inpatient services. Provide diabetes updates for all staff involved in diabetes care ward(s), outpatients and accident and emergency departments.

### Schools, colleges and early years settings

Children and young people spend a lot of their time in education it is paramount that the environment they are in is safe and has policies and procedures underpinning the care that is provided to children and young people with diabetes.

The RCN's *Supporting children and young people with diabetes: guidance for nurses in schools and early years settings* (2013) can also help to guide you in planning care for children and young people in schools. It also sets out the legislation in place to support children and young people with diabetes in schools.

School nurses require regular updates on diabetes management in school (RCN, 2009). Whenever a child or young person is diagnosed with diabetes, or changes school or staff changes occur a school visit will be indicated and the health care plan should be updated accordingly (RCN, 2009). Ideally the school visit will occur before the child returns to school.

School staff will also need regular updates, particularly for pre-school children who move into primary school and children who start secondary school. Intensive insulin regimes mean that school staff must have specific training to administer insulin in school. Refer to *Managing medicines in schools and early years settings* (DH, 2005a) for advice.

## 9

## Safeguarding children and young people

Safeguarding is everyone's responsibility and consequently attending annual safeguarding updates is essential. Many areas have multidisciplinary training courses that involve health, social services, education and the police. This includes the Common Assessment Framework (CAF) – a shared assessment and planning framework used across all children's services, and all local areas in England. Early identification of children's additional needs and promotion of a co-ordinated service to ensure protection is the aim.

Awareness of the local safeguarding policy and the action necessary if there are any concerns is principle. If the children's diabetes team spans more than one social services area, awareness of any difference in policies will be necessary.

Each organisation is required to have a named nurse and doctor responsible for safeguarding (DfE, 2013). Any concerns about the safety of a child should be discussed with the named nurse or doctor. If they are not available, then contact and discuss with social services, following the local safeguarding procedures.

Remember to tell the parents of the child about your concerns, and what action you intend to take. If you refer to social services, then they are required to disclose the name of the person raising concerns to the family.

## Disclosure and Barring Service

On 1 December 2012 the Criminal Records Bureau and Independent Safeguarding Authority merged to become the Disclosure and Barring Service (DBS). CRB checks are now known as DBS Checks.

Ensure all volunteers for activities have had a Disclosure and Barring Service (DBS) check. Check with your manager if you are unsure.

Further information can be found at:

- [www.gov.uk/government/organisations/disclosure-and-barring-service](http://www.gov.uk/government/organisations/disclosure-and-barring-service)
- [www.nidirect.gov.uk/disclosure-and-barring-protecting-children-and-vulnerable-adults](http://www.nidirect.gov.uk/disclosure-and-barring-protecting-children-and-vulnerable-adults)
- [www.disclosurescotland.co.uk/about/vulnerable-groups/how-it-will-work](http://www.disclosurescotland.co.uk/about/vulnerable-groups/how-it-will-work)

It is important to arrange safeguarding supervision sessions with the lead safeguarding nurse for your organisation.

## Protecting yourself

To protect yourself and prevent the risk of any accusations, try not to be alone with children and young people – particularly when you check injection sites (RCN, 2013 – *Protection of nurses working with children and young people*).

## 10

# Continuing professional development

## Relevant study days, conferences and journals

Maintaining professional development through attendance at conferences, study days and reading peer-reviewed journals is essential to ensure you are using up-to-date, evidence-based practice. Subscribe to journals such as: *Pediatric Diabetes*; *Nursing Children and Young People*; *British Journal of Community Nursing*; *Journal of Diabetes Nursing and Practical Diabetes International*; and *Diabetes Digest*. Join Diabetes UK's Education and Care Section and obtain Balance and Diabetes Update. You can also get email news alerts from the Juvenile Diabetes Research Foundation (JDRE). Ensure you are familiar with the documents and publications listed in the appendix.

You can learn a lot when you network with other children's diabetes specialist nurses and offer peer support. Attend some of the key conferences such as:

- Diabetes UK – annual professional conference [www.diabetes.org.uk](http://www.diabetes.org.uk)
- British Society for Paediatric Endocrinology and Diabetes
- International Society for Pediatric and Adolescent Diabetes. For a full listing of international events visit [www.ispad.org](http://www.ispad.org)
- Lilly paediatric symposium.

## Academic courses

There are seven courses and academic modules available to help you develop clinical knowledge, skills and understanding, teaching, audit and research skills. To find out what is available locally and nationally contact:

- your organisation's education and training department
- the local university
- University of York, Warwick University and The University of Birmingham
- regional network
- the RCN Children and Young People's Diabetes Community via the website [www.rcn.org.uk](http://www.rcn.org.uk)

The above are directly related to children and young people's diabetes, however many skills are required by a children's diabetes specialist nurse and there are courses and modules available in the following areas:

- non-medical prescribing and patient group directives
- pump courses
- RCPCH e-learning adolescent health module
- motivational interviewing
- teaching skills
- group facilitation.

## Clinical supervision

It is important that you have a clear understanding of your own role and responsibilities, and where to seek help, support and advice. Ensure you have clear defined pathway for issues of concern. Clinical supervision can be a valuable tool for discussing and reflecting on these concerns, so allow time for this in your schedule.

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## 12

# Appendix: Useful contacts and sources of information

## Internet resources

There are several sources of up-to-date information available on the internet that may be useful to you and the families you are working with. However, you should bear in mind that information published on the web is not always evidence-based, or even true. It can be helpful to direct people towards the following recognised sites:

- [www.nhs.uk](http://www.nhs.uk)
- [www.yorkshirediabetes.com](http://www.yorkshirediabetes.com)
- [www.ispad.org](http://www.ispad.org)
- [www.jdrf.org.uk](http://www.jdrf.org.uk)
- [www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com)
- [www.sign.ac.uk](http://www.sign.ac.uk)

## Charities and patient support groups

### Juvenile Diabetes Research Foundation

19 Angel Gate  
City Road  
London EC1V 2PT  
Tel: 020 7713 2030  
[www.jdrf.org.uk](http://www.jdrf.org.uk)

## Professional resources

### Aventis Pharma Limited

Aventis House  
50 Kings Hill Avenue  
West Malling  
Kent ME19 4AH  
Tel: 01732 584000  
[www.aventis.co.uk](http://www.aventis.co.uk)

### Beckton Dickinson

The Danby Building  
Edmund Halley Road  
Oxford Science Park  
Oxford Road  
Oxford OX4 40G  
Tel: 01865 748844  
[www.bd.com/uk/](http://www.bd.com/uk/)

### Diabetes Care

Bayer plc  
Strawberry Hill  
Newbury, Berkshire RG14 1JA  
Tel: 0845 6006030  
[www.bayer.co.uk](http://www.bayer.co.uk)

### Eli Lilly and Company Limited

Lilly House  
Priestley Road  
Basingstoke, Hampshire RG24 9NL  
Tel: 01256 315999  
[www.lilly.co.uk](http://www.lilly.co.uk)

### International Society for Pediatric and Adolescent Diabetes

[www.ispad.org](http://www.ispad.org)

### Lifescan

50-100 Holmers Farm Way  
High Wycombe  
Buckinghamshire HP12 4DP  
Tel: 0800 121200 (customer care freephone)  
[www.lifescan.co.uk](http://www.lifescan.co.uk)

**Medisense**

Abbott House,  
Vanwall Business Park,  
Vanwall Rd, Maidenhead,  
West Berkshire SL6 4XE  
Tel: 01628 773355  
[www.abbottuk.com](http://www.abbottuk.com)

**Medtronic UK**

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**November 2004**

second edition **July 2011**

third edition **November 2013**

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0345 772 6100

Published by the Royal College of Nursing

20 Cavendish Square

London

W1G 0RN

020 7409 3333

Publication code: 002 474

ISBN: 978-1-908782-79-3