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Occasional Review

Care of the diabetic child in the community*

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Summary and conclusions

Brief admission of the new diabetic child and of a parent to an enlightened hospital for stabilisation, preliminary education, and familiarisation with hospital and community staff is well worth while. The greater the demand for constant control of the highest quality, the greater the need for a close understanding of the psychosocial factors concerned and for clinical skill. The nature of the home and the family relationships should in theory be available from the child's general practitioner at the time of the first referral since he has so much information about the whole family. With the virtual disappearance, however, of mutual consultation in the patient's home in many places, the opportunity for oral communication has declined, and availability on the telephone is not always easy. The busy general practitioner (far less an unknown physician from a deputising service without access to the records) has little time to write a comprehensive letter. In practice a relatively small hospitalbased mobile team of specially experienced sisters who are keen to communicate in the home, the GP's surgery, and the school makes a major contribution to the diabetic

*A lecture delivered at the Royal Hospital for Sick Children, Pendlebury, Manchester, as part of a Novo Symposium on "The Diabetic Child." care of a young population vulnerable to major handicap in what should be the prime of life. Their cost effectiveness may be difficult to prove but it is not at all in doubt especially when the sisters as in this area deal in the community with a wider range of chronic illnesses and handicaps in children.

Insulin-dependent diabetes affects more than one in every thousand British children under school-leaving age. This makes it a common disease when judged against the prevalence $\overset{\text{N}}{\sim}$ of other endocrine and metabolic disorders. It cannot be dismissed as unimportant-since juvenile diabetes is now the commonest single cause of registered blindness in the age commonest single cause of registered blindness in the age \gtrsim group 30-45 years. The increasing evidence that such personal \gtrsim and national burdens may be prevented or indefinitely deferred by achieving new standards of strict control emphasises the need for the best treatment day and night throughout the years.¹ Yet the proportion of child diabetics in a general clinic is small, and it can be difficult to find for them and their parents the time they need. Family doctors have less experience and even less time since the average individual NHS list is unlikely to include even one, while the numbers of other sick people to be seen are large especially at times of epidemics when young diabetics too are likeliest to be in trouble. Care therefore touches on several sensitive issues. Should the child diabetic of be looked after by a consultant paediatrician or a consultant physician? Should the consultant be a generalist or have a ca special interest in diabetes and be in regular touch with advances in the field ? Should generalists refer child diabetics to specialists ? Who should accept responsibility for giving such day-to-day

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advice as may be necessary? Should individual physicians practise what they were taught by their medical school in their generation? Should they fall in line with local clinical practice? Should the school doctor be informed that the child is diabetic? Medicine is bedevilled at times by demarcation lines. It is not *who* cares for the child that matters but the *quality* of the care provided.

Are the nursing services in step with the medical ones? Are the community nurses (hopefully, increasingly practice-based in health centres) in step with their hospital colleagues? Should school teachers and school catering staff know that a child is diabetic? Are some parents wise to insist on keeping the diagnosis secret? Whom should they ring as their first line of diabetic help and advice? Need new diabetic children be admitted to hospital for education and stabilisation? How much pressure should be exerted to achieve the nearest approach to normoglycaemia? Should children and their parents be told about complications?

In each of these questions the individuals most deeply concerned are the children themselves. It is they who must stay in hospital, who need injections, whose eating habits may be changed, whose indifferent control may prejudice education, whose social activities may be modified, whose anxieties may become intolerable, whose parents may be driven apart, whose brothers and sisters may be resentful—and whose eyes, kidneys, heart, and limbs may be under indefinite sentence. Those concerned with their care therefore, from parents to the professional purveyors of medicine, education, and social work must see the limits of their respective roles in the context of the child's health and happiness.

Wherever it is provided, such care should be integrated to make possible the most normal childhood and an education directed toward the most appropriate employment. Clinics operated jointly by physicians and paediatricians who relate closely to their medical and nursing colleagues in the community may achieve these ends more easily.

I shall now describe the clinic and its workings at the Royal Edinburgh Hospital for Sick Children where, at the moment of writing this paper, more than 160 diabetic children and adolescents are under regular supervision. A clinic of this size, developed over 25 years in association with colleagues in both paediatric and adult medicine, has made possible the quiet evolution of a single system of care. This helps the community to avoid to a great extent those conflicting medical and nursing opinions that, although insignificant to the professionals, seriously erode the confidence of parents and children to a point where they may no longer know how to seek what is best.

In hospital

A brief description of our hospital practice is essential to understanding our arrangements for community care. The goodwill of co-operative paediatric colleagues has ensured at this hospital a system in which each medical unit takes an equal share of general acute admissions (so permitting the balanced teaching of students and postgraduates) while developing special interest facilities for the hospital as a whole. Thus all major specialties are well represented without the consultants losing their skill in the general medicine of infants, children, and adolescents. One ward, by common consent some 15 years ago, came to admit all new and old diabetics. The hospital staff on call provide the care-according to a prominently displayed and detailed protocol-for the day of admission only. The rotation of registrars through the unit and the roster of senior registrar duty ensures that they gain diabetic experience. Again with the goodwill of the physicians primarily concerned with diabetes at the Royal Infirmary of Edinburgh all children aged under 12 years referred to them for care are sent on to this unit where we have in the clinic the services of a physician from the adult department. She cares for most of those aged from 14 to 16, preparing them gradually for their first appointment with her at the adult clinic. She is naturally a familiar presence to them at the Royal Hospital for Sick Children in their earlier years, and they are easily transferred to her care in adolescence. Pregnant diabetics at the Simpson Memorial Maternity Pavilion are again in her care, and their newborn infants have been my own special interest since 1948.

The unit's programme of diabetic management applies to all admissions and to all clinic attenders. Insulins are restricted to two highly purified pork preparations (one short-acting; the other intermediate-acting) with the recent experimental addition of one highly purified beef preparation in similar short and intermediate products. Food conforms to a normal healthy diet and not only is the nature of surveillance agreed but so is the desirable standard of control. Both are intermittently reviewed. Diabetic care of the young in Edinburgh therefore passes along a back division that has played together for a long time. An occasional scissor movement brings me back into the line after a few years while a careful cross-kick when appropriate may place a relevant problem safely into the hands of a physicianpaediatrician partnership on the other side of the city.

Fundamental to the efficiency of the service is the nursing team. Trained staff on the unit at the Royal Hospital for Sick Children are expert in dealing with diabetic emergencies, in handling and reassuring frightened children and parents, and in teaching with patience the simple elements of care. Trained staff in the outpatient clinic, linked to paediatric-trained nurses in the community, constitute a small, mobile, and very effective home care team that operates throughout the Health Board Area of Lothian. The nursing officer in charge and the senior departmental sister both had extensive experience in the unit and did much to evolve its system of diabetic management.

ADVANTAGES OF ADMISSION

Although on humanitarian grounds alone small children should be spared the unhappiness of admission to hospital and separation, each case must be judged on its merits. The balance for and against admitting the newly diabetic child is in my opinion firmly in favour of admission and depends on the unit's ability to communicate sympathy, security, and efficiency. At least one parent should be admitted with the diabetic child for all or part of the time. The positive gains are as follows:

(1) The parents develop trust in the staff as a result of closely observing an efficient team restoring a very ill, dehydrated, and ketotic child to the path of secure progress.

(2) During those few hours the staff can teach much more effectively since they have the child with them as a living model. The parents learn in these conditions much better than from a book how to recognise dehydration and the breathing pattern of air hunger, the smell of ketones in the breath, and the test for ketones in the urine. These dramatic moments imprint on their memories what may not be fully communicated by subsequent lecturing. It should make unnecessary any subsequent lapse into severe ketoacidosis except perhaps for children in very remote places or with dull or uncaring parents.

(3) Parents, commonly strangers to a hospital environment, relax as they become familiar with it and welcome the chance to discuss with the staff on duty their thoughts about treatment as they arise. Commonly, they also sense from looking at other children and talking to other parents that there are much worse problems than diabetes.

(4) Even when the child has not been acutely ill on admission, the hospital stay increases the possibility of supervised treatment by the parents. More important, however, the parents of all admissions meet not only the unit nursing staff but the home care sisters. Their unity of purpose of method is clear. One nursing team is seen to be handing over to the other so that the home care sisters are already familiar friends when they turn up in the patient's home. They are manifestly an extension of the hospital into the community, conducting the same programme of care and in daily contact with the hospital team. This is immensely reassuring. (5) The presence of child and parent in hospital for a few days provides a preliminary indication of parental ability and stability. A prediction of possible future difficulty is attempted, and an effort may be made to prevent it.

(6) An insulin reaction may be induced safely in the parents' presence so that they may watch their child's individual pattern of hypoglycaemia—and feel reassured by their success in treating it under supervision.

(7) Early contact is made with the general practitioner and with the school health service. It has been our practice to place a copy of the system of diabetic care in the hands of the doctors concerned, and a plea is made for uniformity in management.

(8) The following check-list is completed before discharge the parent retaining one copy, the case record another.

Good food system explained
BDA Carbohydrate exchange list supplied
Diabetic food weighing scales obtained
Successful Diabetic Cookery seen
Carbohydrate Countdown seen
Colour vision tested
Urine test instruction complete-glucose; ketones
Testing agents obtained—glucose; ketones
Urine test result book prepared
Insulin(s) prescribed and obtained
Insulin syringes (BS 1619 glass) prescribed and obtained
Insulin needles supplied (under 16 years) or prescribed and obtained
Syringe sterilisation demonstrated
Spirit-proof case (Hypoguard) seen
Spirit prescribed and obtained
Insulin injector demonstrated; obtained
Insulin reaction demonstrated and treated
Glucagon prescribed and obtained
Long needles for glucagon injection obtained
Identity disc, pendant, bracelet, or tube obtained
Introduction to home care team
Family doctor informed of planned discharge date
Address of British Diabetic Association provided
School health service informed by hospital (if still at school)
Young diabetics leaflet [†] supplied for school teachers if relevant

(9) No attempt is made to reach perfect diabetic control in hospital since climate, activity, and meal times are artificial. The child is normally discharged in one week with the assurance that the home care team will call on the family next day.

In the community

Duration of stay for newly diabetic children in this hospital was measured in weeks from the 1920s to the end of the 1950s, and the child was quite often transferred after that to a convalescent home. With the formation of a diabetic team, however, the average duration of stay was 6.5 days by 1970 against a national average of 12. By 1976 this hospital's average was about 4.5 days against a national average of 8. The home care team makes this possible. Its true value, however, lies not in the duration of first admission alone but in the reduced need for readmission, the earlier involvement of the hospital in correcting ketoacidosis, the better knowledge obtained about psychosocial factors at home, the relief of maternal and school teacher anxiety, and the fewer school absences. Few of these advantages are quantifiable, but those who experience them know that children, parents, school teachers, and the hospital system all benefit substantially.

NEW PATIENTS

The home care team sister who was concerned with the family in the hospital visits them on the day after discharge, frequently thereafter until confidence is sufficient, and then as

†Could be used also by lecturers at a technical college as a general guide.

may be indicated. Parent and child are naturally more relaxed and receptive in their own environment. The technicalities of insulin injections, meals, and monitoring are gently imparted to a degree of which the family is judged capable without undue strain at this early stage.

The informal nature of these calls (the sisters do not wear uniform) makes possible a continuing assessment of the homeits organisation, its finances, alcoholism, the stability of the parents and of the marriage, the relationships between parents and children and between the children themselves, the deftness with which necessary procedures are conducted, and the extent to which parents are likely to seek further education toward optimal control. Experience enables the sisters to recognise more or less quickly signs of dullness, carelessness, or resentment at one extreme and obsessional neurotic behaviour, excessive anxiety, or depression at the other. Such knowledge often makes possible anticipation and modification of those psychosocial factors that are important beyond all doubt in diabetic children, adolescents, their families, and eventually the diabetic adults who emerge from the interactions in this fiery crucible. Universal success is not claimed-partly because the team is small and partly because many psychosocial problems are already fixed when diabetes is diagnosed. The results, however, are far superior to those obtained when we knew little of the background, accepted at face value the urine record book presented at the clinic, and depended on relatively brief and infrequent outpatient interviews for our manipulation of the child's diabetic control. The service is available to all but inevitably devotes more care in the long term to those families that are least well endowed or have the greatest problems, or both.

The visit of a home care sister to the child's school prepares the staff for the child's early return. She discusses with head and class teachers the recognition of hypoglycaemia, its effects on performance and emotion, its prevention, and its treatment. In this work she is helped by the attractive leaflet Young Diabetics prepared by the Scottish Health Education Group.[‡] It was written by the Scottish Committee of the British Diabetic Association and is reproduced from the unit's alphabetical flip-chart "Index of First Aid and Health Problems for Schools." The home care sister briefs the school nurse about such help as may be needed and explains to the catering staff the food needs of the diabetic child. There should be no segregation of the diabetic at school lunch-and no special tray. Good food for healthy children is good for diabetics if given in the right amount at the right time. Sweet puddings are undesirable (healthy children could do with less of them too), and a variety of fresh fruit or biscuits and cheese should be substituted.

The home care sisters may also help prepare school staff who wish to take a diabetic pupil on a camping or cruising holiday. They may not have been adequately briefed by parents, who may sometimes take dangerous chances in their anxiety that their child should go with friends.

CONTINUING CARE

Guidance and reassurance on diabetic treatment

Parents will have available to them simple books² (J W Farquhar, to be published) about the system of care used and how to deal with common problems. The special version for teenagers deals specifically with relevant sexual, educational, and social matters. There are times, however, when being alone and frightened with the printed word is no substitute for the warmth and reassurance of the familiar voice of a person whom the parent or young person or both trust.

A home care sister may be telephoned at the Royal Hospital for Sick Children clinic early in the morning and again in the late afternoon on schooldays to answer inquiries from home

‡ Inquiries please to the Scottish Health Education Group, Health Education Centre, Woodburn House, Canaan Lane, Edinburgh EH10 4SG

about unwell diabetics-the meaning of urine or blood test results, what to do about breakfast if the child feels unwell, fitness for school, adjustment of the insulin dose, the need to call the family doctor, and the need to bring the child to hospital. When the sisters are unavailable calls go direct to the diabetic unit where staff deal with the immediate problems, contact the general practitioner if necessary, arrange admission if required, and inform the home care sisters as soon as possible so that a home visit may be arranged if necessary.

Home visits

Parents often telephone not just to discuss some problem of management but because they have themselves reached breaking point in anxiety or depression. A home visit may relieve much tension or introduce the parent to the general practitioner or the hospital consultant. Such problems as the suicidal attempt by a mother some years ago who subsequently delivered an unintentional rebuke by saying, "I didn't know you were interested in the mothers" do not and should not now occur. We should also try to avoid or at least reduce the sad events among young people described by MacGregor.³

Such home visits commonly occur during the school day when mother is alone. She can speak freely of family affairs without the children listening and without the presence of the medical or nursing students that can inhibit a disturbed parent in a teaching hospital from even asking for a confidential interview in privacy. She can open her heart about many intimate problems "over a cup of tea." This alone is a safety valve that can prevent disaster.

Confirmation of control

Every experienced doctor recognises patients in whom the perfect record of home urine test results cannot be reconciled with the child's appearance, weight loss, frequency of admission, or results of blood tests at the clinic. He can spend much time attempting to solve the enigma by questioning mystified or inscrutable parents and children. The truth is important. If the record is fictitious he can say so, declare his willingness to help improve control, and wait until the parents agree or the child is old enough to assume personal charge. On the other hand, if the record is true he views the problem differently and seeks to understand and correct it. The home care team, with parental consent and the co-operation of school and practice nurses, can obtain "spot" specimen of urine and blood at different times of the day at home and at school. Dextrostix and a small monitor-for instance, Hypocount-in the nursing bag or the BH Glycemie 20-800 test are invaluable aids. The sister can also teach school nurses how to use these as a check on doubtful symptoms of hypoglycaemia. Indeed, a 24-hour profile is perfectly possible as a superior guide when adjusting insulin doses.

Harmonising roles

There need be no disharmony between the hospital clinic and the primary care and community health services. Each important contact with the home care team or the unit staff should be recorded. Each action, of which the general practitioner or relevant clinical medical officer should know, should be communicated. Matters of health, primary care or school level, can be dealt with there without concerning the hospital clinic if no special help is required to stabilise the diabetes.

We have wanted very badly for some years now an experienced clinical medical officer seconded to the diabetic clinic to participate on each occasion. She would liaise after each with her colleagues in school medicine. This would be most helpful from the time the diabetic child first joins the school right through to appropriate vocational guidance in senior school.

Coping with the impossible

In a small proportion of families various psychosocial problems endanger life itself. Some children are safe only when in hospital and have been known to go to school from there for many months. Others run away from home or get into trouble for antisocial acts. Barnardo's provision of a diabetic hostel for such young people in Edinburgh⁴ has enabled them to attend school, to be well fed, to live under good conditions, to maintain contact with their families, to witness an alternative way of life, and perhaps to learn something of self-care. The work is both difficult and expensive. The possibility of its continuation is often questioned but for more than a decade now it has stood "as a rock in a weary land ... a shelter in the time of storm." It is a far superior alternative to long-term admission to hospital, and it is substantially less expensive.

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What is the likely effect of gazing directly at the tropical midday sun? How dangerous is it to view an eclipse of the sun by the naked eye, and what precautions should be taken when watching an eclipse?

Visual disturbances from looking at the sun have been known for a long time, and Galileo was reported to have injured his eye by looking at the sun with his telescope. Non-mechanical thermal injuries to the macula usually result from prolonged gazing at the sun at any time, including during a solar eclipse, which may be practised for therapeutic or religious purposes or when under the influence of drugs. The eyes are normally protected from injury by the sun by the fleeting duration of the glance and by lack of fixation, and only prolonged fixation leads to injury. Young people are more susceptible to macular injury due to greater transmissibility of the lens. The visual symptoms of prolonged exposure to the sun include after images, photophobia, metamorphopsia, and a dense scotoma that usually appear within 24 hours and may last for several weeks to months; in some this may even be permanent. The retinal findings may vary from normal to macular oedema and to parafoveal white spots surrounded by a zone of mottled pigmentation. A typical macular hole may be noticed in severe cases. The oedema usually subsides within a fortnight. Retinal pigment epithelial changes (loss of melanin granules) at the macula without affecting the overlying retina may be noticed in some cases. There is no effective treatment though corticosteroids administered either systemically or given as retrobulbar injection, topical mydriatic agents, and dark glasses have all been tried. In most cases the vision improves within a few weeks, and the scotoma if it is still present tends to diminish. The prognosis though variable is generally good, especially when the symptoms including the scotoma subside during the first month. The safest method to observe an eclipse if it is absolutely essential is to allow the light from the sun to pass through a pinhole in a piece of cardboard and to focus the image on a second piece of black cardboard held beneath it when a clear image of the sun can be seen on the second cardboard. Welder's goggles that correspond to British Standard Specification (BSS 679/1947) or the US Federal Specification (GGG-G 511A) may also be used since they cut out most of both the infrared and the visible rays.¹ ²

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