THIS GUIDELINE DESCRIBES THE MANAGEMENT OF 
CYSTIC FIBROSIS 
IN THE SCHOOL SETTING INCLUDING THE ROLE OF COMMUNITY 
CHILD HEALTH MEDICAL AND PUBLIC HEALTH NURSING SERVICES

This guideline is designed to assist both health-care and non-health-care personnel involved in the care of children

This guideline should be read in conjunction with the Administration of Medicines in Schools Policy

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**Policy Reference:**

**Date of Issue:** 1st May 2013

**Prepared by:** Alison MacRobbie

**Date of Review:** 1st May 2015

**Lead Reviewer** Lesley Blaikie, Raigmore Hospital & Jane Davis, Inverclyde Royal Hospital

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**Date:** 1st May 2013

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**Date:** 1st May 2015

**Distribution**

- Medicines in Schools Steering Group & Website
- Public Health Nurses
- Health Visitors
- Consultant Paediatricians
- Consultant Community Paediatricians
- Paediatric Clinical Nurse Specialists
- Paediatric Pharmacists
- Community Pharmacists
- GPs
- Children’s Ward
- Children’s Services Lead Nurses Health and Education
- Education & Leisure Services The Highland Council and Argyll & Bute Council
- Support for Educational Needs Staff
- School Head Teachers
- Early Years leads
- Early Years providers
- The Orchard
- Children’s Commissioner

**Method**

- CD Rom
- E-mail ✓
- Paper ✓
- Internet ✓
### Description of clinical condition

**Cystic Fibrosis**

This is an inherited condition which affects both boys and girls. It makes the mucous in the body thicker and stickier than normal.

In the lungs this can lead to chest infections and progressive lung damage.

In the pancreas it blocks digestive enzymes meaning food cannot be absorbed properly and the child becomes malnourished, delayed puberty and poor growth. With optimal treatments growth should be maintained within normal limits.

In the liver it can make the bile salts thicker which can cause liver damage.

Many sufferers have sinusitis - inflammation in body spaces leading to pain e.g. above and below the eyes.

### Requirements at school

*Please liaise with local CF team for advice*

Children with cystic fibrosis (CF) should not be taught in the same classroom if possible as there is a high risk of cross-infection between CF patients, especially if coughing. If in the same room, they must be kept apart and the room well ventilated.

CF children are at risk of infection from contaminated equipment such as eating and drinking utensils and from hand shaking. All children and staff should be encouraged to have effective hand washing skills.

CF patients are at risk of infection from other children. They pose little risk to other healthy children.

CF children may require extra snacks and energy rich foods should be encouraged. They often feel full quickly and have a poor appetite.

### Complications at school /pre-school

1. **Fatigue**
   - A quiet area may be required for rest and for physiotherapy

1. **Isolation**
   - Feeling different
   - Priority setting – treatment verses fun

1. **Behavioural issues**
   - Eating problems – need high calorie, high fat, high protein diet intake, encourage regular snacks.
Often require enzyme medication before and during all snacks (containing fat) to aid digestion of food. A list of fat free snacks is available from the Cystic Fibrosis Nurse Specialists.

Manipulation – staff need to be aware.

1d. Breathing problems (Wheezing)  
Inhalers may be required  
- blue reliever inhalers (salbutamol, Terbutaline)  
May require antibiotics during school day  
May require oxygen therapy

1e. Absences  
Children may experience frequent absences from school. Essential to liaise with CF Team if attendance is falling. Very much appreciated if schools are able to supply home work during periods of hospitalisation.

1f. Follow-up  
Parents should be advised of any concerns. Cystic Fibrosis Team should be contacted for advice or if schools have concerns or need an update.

1g. Issues for school/pre-school trips  
Cystic fibrosis should not present a problem provided the following principles are followed:  
- Regular meals and between meal snacks  
- Awareness of fatigue if sustained physical activity  
- Children need to avoid use of spas and areas where there are damp conditions.

Changes in treatment should be discussed well in advance of a trip especially if there is an overnight stay.

The degree of supervision required for the child should be discussed with parents and cystic fibrosis team.
### Responsibilities of Organisations

| **Health** | There will be school doctor advice and support for each school.  
There will be public health nurse advice and support for each school/pre-school.  
Community Child Health will be aware of all CF children in Highland. Care will be led by the Cystic Fibrosis team based at Raigmore hospital for North Highland health partnership areas.  
Advice will be provided by the team at Royal Alexandra Hospital for Argyll and Bute partnership area.  
The Cystic Fibrosis team are available to provide relevant training on the management of CF in schools for school staff.  
Liaison in provision of relevant clinical guidance.  
Health professionals contribute to the Child’s Plan as appropriate detailing level of support offered |
| **Education** | Contribute to the Child’s Plan detailing level of support offered  
Ensuring relevant staff receive appropriate training.  
Ensuring appropriate facilities and procedures are in place in education environments to manage children with CF.  
Liaison with parents in relation to sharing information on health and medicine requirements for their children. |
| **Social Work** | Contribute to Child’s Plan as appropriate detailing role and support offered  
Ensuring relevant staff receive appropriate training.  
Ensuring appropriate facilities and procedures are in place in education environments to manage children with CF.  
Liaison with parents in relation to sharing information on health and medicine requirements for their children. |
### Responsibilities of personnel involved

| **Consultant** | Letters from clinics will be sent to linked doctor in community child health |
| **Community Paediatricians** | School doctors should be aware of all CF children within their schools.  
The Highland Council Partnership Area Liaise with the CF specialist team based at Raigmore should issues arise in school in relation to the individual's Cystic fibrosis. Inform CF Team when a child has been reviewed.  
Argyll and Bute Council Partnership Area Liaise with the CF specialist team based at Royal Alexandra Hospital should issues arise in school in relation to the individual's Cystic fibrosis. Inform CF Team when a child has been reviewed |
| **School Nurses** | Should ensure that they liaise with the Cystic Fibrosis Specialist Nurses for guidance and advice for all matters relating to the young persons Cystic Fibrosis. All other School Nurse responsibilities and interventions should remain as core interventions. Inform Cystic Fibrosis Team when a child has been seen by the School Nursing Team. |
| **Parent** | - Contribute to their child’s Plan identifying their responsibilities to support the management of care of their child’s condition within school  
- Consent to the school being informed of their child’s condition, symptoms and treatment  
- Keeping school information current  
- Providing school with relevant snacks, food supplements, emergency contact details and all medication...  
- Parental responsibility to ensure these medications are kept up to date |
| **Education staff e.g. teachers, playgroup leaders, ancillary staff** | - Attend training on Cystic Fibrosis and how to recognise symptoms and manage them and keeping this information up to date  
- Liaison with health and social care staff |
Requirements for implementation

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| Health staff | - Continuing professional development  
- Updates on CF at least every 3 years unless new developments  
- Provided by specialist CF Nurse  
- Content to include – prevalence, aetiology, progression, management of treatment & complications, impact on lifestyle, issues for relevant age groups, policies in place |
| School/pre-school and social work staff | - Update on CF at least every 3 years unless changes to management  
- Specific training on individual children in care as and when need arises  
- Provided by CF nurse  
- Content to include summary of condition, issues applied to school re triggers and prevention, relevant treatment, when to refer, policies in place |

| Equipment/facilities | Storage of supplies from parents for treatment of breathing difficulties, food supplements and medication and procedure for access  
A quiet area for physiotherapy and/or rest if required |

| Documentation | Child’s Plan indicated responsibilities of all parties and level of support offered with links to Child health care plan  
Record of incident |

Referral and liaison
Referrals from the hospital CF nurse and clinic consultant via a link member of Community Child Health Department medical staff (includes all correspondence).

Liaison with CF nurse is particularly important at school entry and before transfer to secondary school from P7, and on any school transfer.

Exceptions
- School/pre-school not advised by parent of child’s condition  
- staff member declines to provide treatment

In these instances it would be appropriate to contact the child's parents or phone for medical assistance.

References
Cystic Fibrosis Trust, 11 London Road, Bromley, Kent BR1 1BY  
www.cftrust.org.uk
Appendix I

Staff agreeing to administer medicines

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