

**ANNUAL REPORT OF THE  
BRITISH ARTIFICIAL NUTRITION SURVEY  
(BANS)**

**Committee of BANS**

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## SUMMARY

### 1. PREVALENCE AND GROWTH OF HOME ARTIFICIAL NUTRITION

- **HETF and HPN.** It is estimated that towards the end of 1998 there were more than 12,000 on home enteral tube feeding (HETF) and more than 360 patients on home parenteral nutrition (HPN). The annual growth of HETF was estimated to be up to about 20%, and for HPN,  $\geq 5\%$ . Studies in East Anglia also provide some validity to data submitted to BANS from hospitals and the community.
- **HPN.** Independent information obtained from 38 pharmaceutical advisers to Health Authorities serving a population of 17.3 million revealed that in the latter half of 1998 the point prevalence of HPN was 8/million of population. There was good agreement between this information and that obtained independently by BANS reporters ( $r=0.76$ ), although the BANS data suggested a prevalence of 6/million population. Both sets of data suggested large variability in prevalence in different Health Authorities (0 to  $\sim 30$ /million), which may reflect variable attitudes to HPN and variable expertise for dealing with HPN.

### DIAGNOSES

- **HETF.** The age distribution of 14,284 patients starting HETF between 1996 and 1998 was bimodal, with a peak in the first decade of life and a second larger peak in the seventh decade. The commonest overall diagnosis was cerebrovascular accident (CVA), which accounted for 31% of all diagnoses, and 50% of diagnoses in patients over the age of 70 years. Multiple sclerosis was the commonest diagnosis in patients aged 30-40 years (20%), oesophageal cancer in those aged 50-60 years (32%) and cerebral palsy in children (19%). Malignancies other than oropharyngeal and oesophageal were relatively uncommon accounting for only 2.8% of all diagnoses.
- **HPN.** The age distribution of 244 patients starting HPN between 1996 and 1998 was also bimodal, with peaks in the first decade of life involving a heterogeneous group of patients, and a second larger peak in the fourth decade of life, involving mainly Crohn's disease. HPN was practiced 20-40 times less frequently than HETF.

### OUTCOME

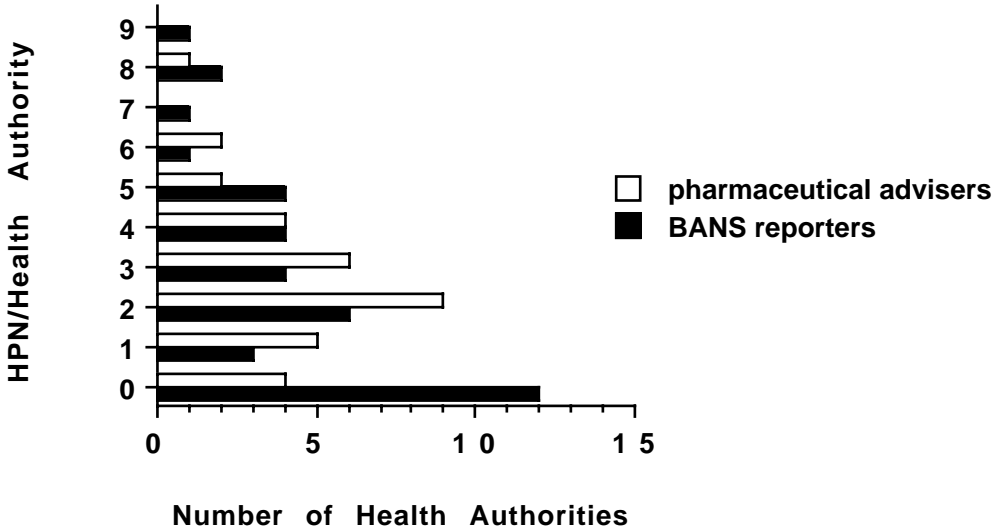
- **HETF.** The overall patient status one year after starting HETF ( $n=8832$ ) was as follows: 22.4% died whilst on HETF; 13.6% returned to oral feeding; 62.0% continued to receive HETF; and 2% withdrew/refused HETF or were in hospital at the time of the assessment. Patients with cerebral palsy, cystic fibrosis, and multiple sclerosis had a relatively low mortality, whilst on HETF (2-12%), whilst patients with motor neurone disease, dementia and malignancy had a higher mortality whilst on HETF (30-60%). Patients with CVA aged over 75 years were 3-4 times more likely to die whilst on HETF and less likely to return to oral feeding, than those aged less than 65 years.
- Return to oral feeding essentially did not occur in patients with motor neurone disease, but it did so in other groups of patients (e.g 13.6% by one year in those with a CVA). Thus, unnecessary HETF may be avoided by intermittent assessment of swallowing.
- **HPN.** The outcome of patients on HPN ( $n=246$ ) differed from that of HETF ( $p<0.001$ ). At one year only 4% died whilst on HPN, 11.4% returned to oral feeding and 82.1% continued on HPN (2.4%, 14.9% and 79.3% respectively for Crohn's disease ( $n=101$ )).
- **HETF and HPN.** Patients on HETF and HPN spent a very small proportion of their time in hospital ( $<1\%$  for HETF,  $<2\%$  for HPN). This saves substantial money for hospitals but places demands on the carers, who are often family members.

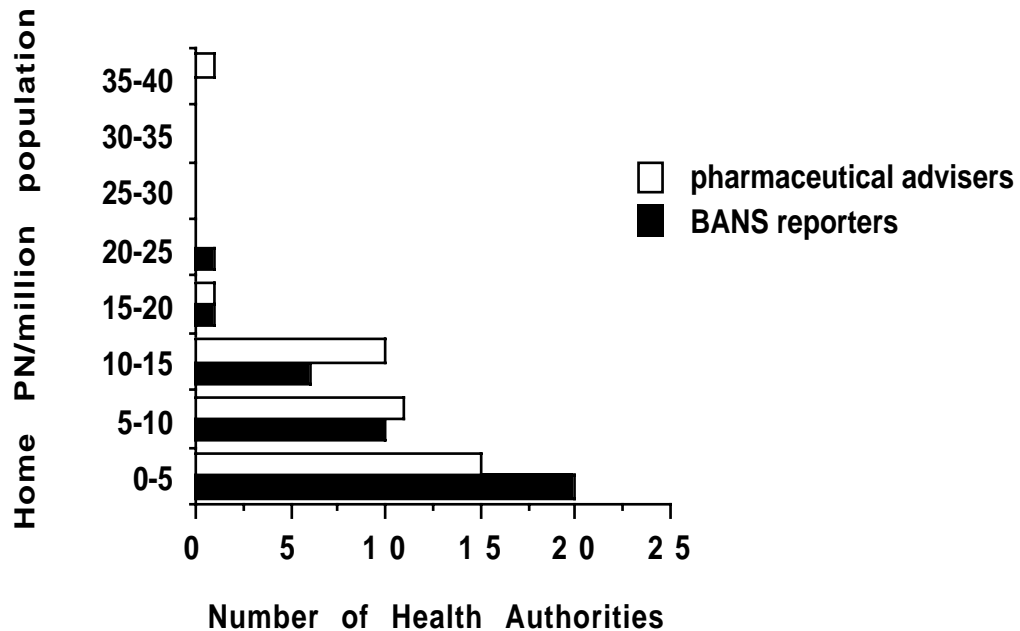
## 1. ABBREVIATIONS

ANS	Artificial nutritional support
HANS	Home artificial nutritional support
PN	Parenteral nutrition
HPN	Home parenteral nutrition
ETF	Enteral tube feeding
HETF	Home enteral tube feeding
BANS	British Artificial Nutrition Survey

## 2. PREVALENCE AND GROWTH OF HOME ARTIFICIAL NUTRITION (HANS)

- 2.1** The report of the 1997 BANS survey emphasised caution in extrapolating prevalence data obtained from part of the country to the whole country. In 1998 additional information was sought to help assess the validity of some of the community prevalence data obtained by BANS, and at the same time obtain information on the variability in prevalence between Health Authorities or regions.
- 2.2** A request was made to 126 pharmaceutical advisers to individual Health Authorities/Health Boards to provide information about the number of patients receiving home parenteral nutrition (HPN) in their Health Authority in the latter part of 1998. The results were compared with those obtained by BANS reporters at a similar time (within 3 months).
- 2.3** The pharmaceutical advisers provided information on 38 Health Authorities (30% response), which served a population of 17.3 million ( $0.45 \pm 0.18$  million per Health Authority).
- 2.4** Thirty-eight of the pharmaceutical advisers provided the actual numbers of patients receiving HPN in their Health Authority, and the other 5 provided estimated numbers (corresponding to 11% of the total number of patients on HPN).
- 2.5** There was striking variation in the point prevalence of HPN (number of patients receiving HPN at a given point in time), irrespective of whether the prevalence was expressed as the number per Health Authority (first graph below) or per million of population in these Health Authorities (second graph below). For example, the point prevalence ranged from 0 to 36 per million of population according to the pharmaceutical advisers, and from 0 to 24 per million according to BANS reporters.





**2.6** There was a significant relationship between the point prevalence of HPN obtained by the BANS reporters and pharmaceutical advisers ( $r=0.76$ ;  $p<0.001$ ;  $n=38$ ).

**2.7** The total number of patients receiving HPN in the 38 Health Authorities was 6 per million of population, according to the BANS reporters, and 8 per million, according to the pharmaceutical advisers (in agreement with commercial estimates).

**2.8 Comment.** There was general agreement between the information obtained by the BANS reporters and pharmaceutical advisers. The following explanations are suggested for some of the differences: the data were not collected at exactly the same time; the BANS reporters may not have been aware of all the patients on HPN in their area, especially those whose responsibility was limited to local hospitals; and a few of the patient numbers were estimated rather than actual values. Both sets of results suggested marked variation in the point prevalence of HPN. These variations are difficult to explain, but they may be related to different attitudes and experience in HPN in different Health Authorities.

**2.9** During the re-organisation of nutritional support services in Avon Health Authority (population, 0.98 million) a central service for co-ordinating and monitoring HETF in the entire Health Authority was established in 1997. Data acquired during the 1998 pilot period were sent to BANS for analysis. These revealed that at the end of 1998 there were 276 patients (184 and 76 children) receiving HETF, or a point

prevalence of 282 /million of population. Only two patients were receiving HPN at that time. 122 new patients were started on HETF during the year, but none were started on HPN.

- 2.10** An independent survey carried out in the Trent region (population 5.0 million) in 1999 revealed that the point prevalence of HETF was about 250/million of population, and for HPN, 4/million of population.
- 2.11** Another independent survey carried out in East Anglia in 1997 revealed that ~150 patients/million of population were receiving HETF and a growth rate of ~20% per year. There were four-fold more patients receiving HPN in East Anglia (8/million of population) than in Avon Health Authority (2/million population). HPN has continued to grow in East Anglia in 1998 as well as in 1999.
- 2.12** The survey in East Anglia obtained similar data on point prevalence to those submitted independently to BANS (hospital ETF, 119 v 142; hospital PN 46 v 46; HETF 240 v 243; and HPN, 10 v 10).
- 2.13** Preliminary analysis of data obtained by BANS during 1998 and additional data from regional studies suggest a continued high growth rate for HETF (over 20% per year). Data from BANS (1998) suggest that diseases of the central nervous system accounted for 64% of the increase in HETF, with cerebrovascular accident being the commonest diagnosis. The point prevalence of HPN, calculated using BANS data, increased by over 10% in 1998. The total number of patients receiving HPN in the UK at the end of 1998 may have been close to 500. This approximate estimate also takes into account data provided by home care companies.
- 2.14** At the end of 1998 (31st December) there were 10864 registered recipients of HETF (total point prevalence in adults, 8014, and in children, 2832) and 348 registered recipients of HPN (284 adults and 64 children). During 1998 there were 5910 new registrations for HETF (5008 adults and 811 children) and 98 new registrations for HPN (84 adults and 24 children), the largest ever recorded in the U.K.
- 2.15 Comment.** The data indicate substantial regional differences in the prevalence of HANS, particularly HPN. They also suggest continued rapid growth of HANS, which is more rapid for HETF than HPN. The studies in East Anglia provide some validity to the data submitted to BANS. However, because of incomplete registration from other parts of the country, analysis of BANS data alone will underestimate the prevalence values of HANS in the U.K. Although uncertain, it is estimated that at the end of 1998 there were more than 350 patients receiving HPN, and more than 12,000 patients receiving HETF in the UK.
- 2.16** The annual registration forms containing information on the prevalence of ANS were obtained from 217 centres between September and December 1997. In early 1998, centres that had not responded despite a reminder, were asked to complete a short questionnaire requesting information on the prevalence of ANS and the

presence of a nutrition team in their centres. Information obtained from these centres (n=48) was compared with data obtained from the annual registration forms.

	Centres completing annual registration forms (n=217)	Centres not completing annual registration forms (n=48)
ETF in hospital (per 100 beds)	2.8	3.4
PN in hospital (per 100 beds)	0.9	0.7
HETF (per 100 beds)	6.1	5.8
Presence of nutrition team (%)	37	43

**2.16 Comment.** The prevalence data and the frequency of nutrition teams in centres that returned the annual registration form and those that did not, were similar.

### 3. DIAGNOSES

#### 3.1 Distribution of diagnostic categories among registered adults on HETF according to age category\*

	16-54 y (n=2379) %	55-64 y (n=1197) %	65-74 y (n=1990) %	>75 y (n=2448) %	>16 y (n=8014) %
Cardiac disease	2	2	1	1	1
Central nervous disease	53	50	64	80	64
Genito-urinary disease	12	10	9	6	9
Gastrointestinal disease	23	34	23	11	21
Respiratory disease	8	2	1	1	3
Other diseases	2	2	2	1	2

\*results are expressed as percentage of the reported point prevalence in 1998

### 3.2 Distribution of diagnostic categories among registered children on HETF according to age category\*

	0-4 y (n=1821) %	5-9 y (n=502) %	10-15 y (n=509) %	<16 y (n=2832) %
Cardiac disease	4	2	3	3
Central nervous disease	35	49	41	39
Genitourinary disease	29	22	15	25
Gastrointestinal disease	10	6	12	10
Respiratory disease	6	14	26	11
Other diseases	16	7	3	12

\* results are expressed as a percentage of the reported point prevalence in 1998

### 3.3 Distribution of diagnoses /conditions among registered patients on HETF according to age\*

	0-15 y (n=2832) %	16-54 y (n=2379) %	55-64 y (n=1197) %	65-74 y (n=1990) %	>75y (n=2448) %
Cerebral palsy	19	7	0	0	0
Congenital handicap	13	3	1	0	0
Cystic fibrosis	9	7	0	0	0
Congenital malformation	5	0	0	0	0
Inborn error of metabolism	4	0	0	0	0
Cerebral trauma	2	8	3	3	1
Failure to thrive	2	0	0	0	0
Cerebrovascular disease	1	6	24	44	65
Cancer: oesophageal	0	9	18	14	4
oropharyngeal	0	3	9	4	2
gastric	0	1	1	1	0



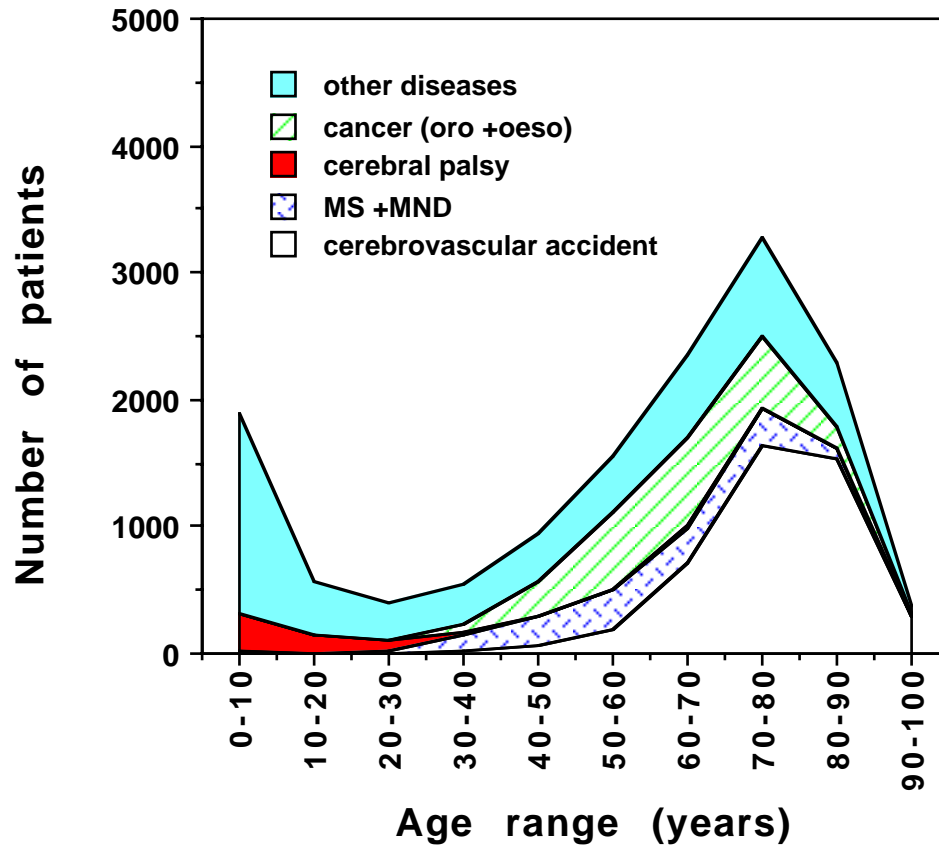
head & neck	0		1		1		1		0
other	1		1		1		2		1
Multiple sclerosis	0	20		8		2		2	
Motor neurone disease	0		3		7		6		4
Parkinson's disease	0		0		4		4		1
Dementia	0		0		1		2		4

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\* results are expressed as a percentage of the reported point prevalence in 1998

**3.4 Diagnoses (number) of registered patients starting HETF between 1st January 1996 and 31st December 1998, according to age (n=14284)**

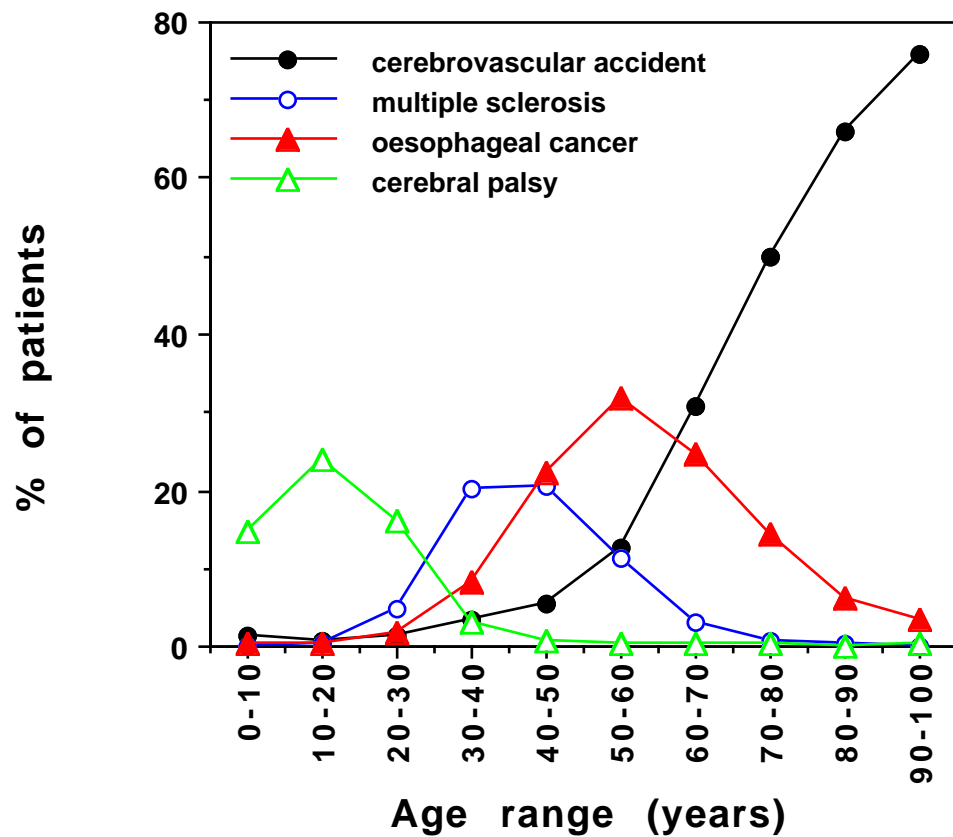
## HETF: diagnoses at different ages



There is a clear bimodal age distribution, with the second and larger peak occurring in patients aged 70-80 years. This second peak is mainly due to use of HETF in patients who have suffered a cerebrovascular accident. Cancers of the oropharynx (oro) and oesophagus (oeso) accounted for 2395 registrations or 85% of all cancers. Cerebrovascular accidents accounted for 4484 registrations, and motor neurone disease (MND) and multiple sclerosis (MS) in combination for 1365 registrations.

**3.5 Diagnoses (% of total) of registered patients starting HETF between 1st January 1996 and 31st December 1998 - cerebrovascular accident, n=4484; oesophageal cancer, n= 1966; multiple sclerosis, n=601; and cerebral palsy, n=531.**

## HETF: diagnoses according to age

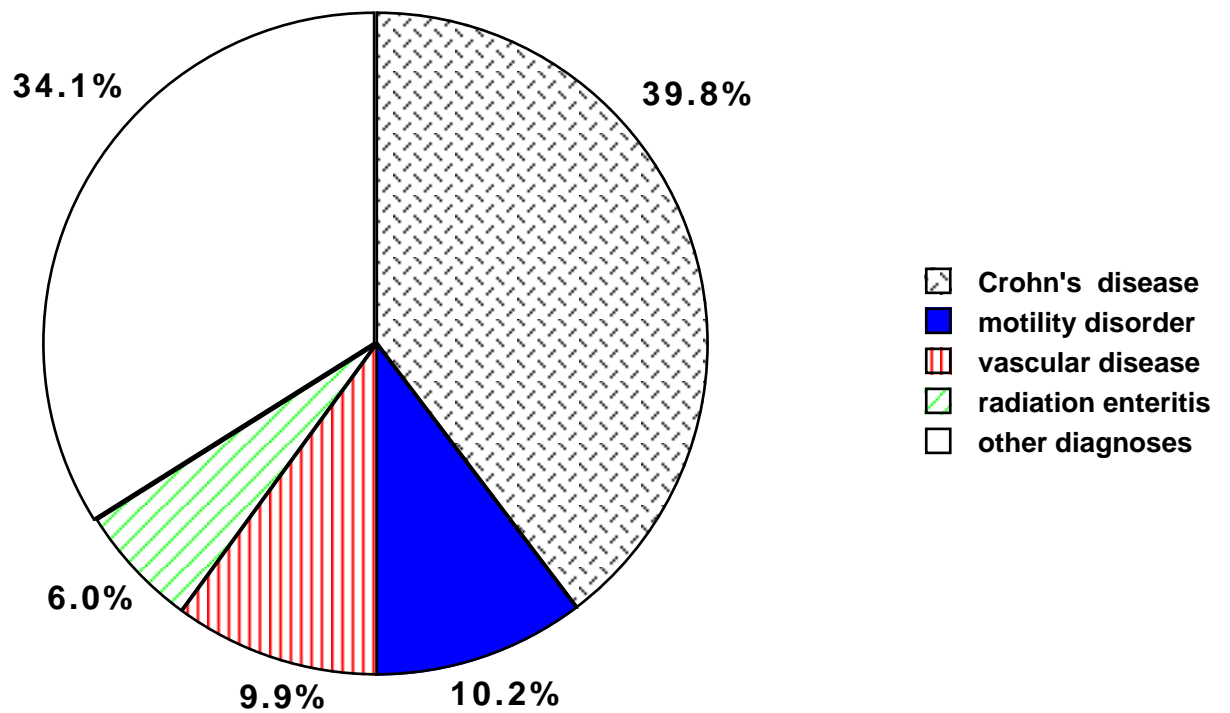


The commonest diagnosis in adult recipients of HETF is cerebrovascular accident, and in children it is cerebral palsy. Multiple sclerosis was the commonest diagnosis in patients aged 30-40 years (20.3%), oesophageal cancer in those aged 50-60 years (31.8%), and cerebrovascular accident in those aged over 60 years (50.0%). Cerebral palsy accounted for 14.8% in those aged 0-10 years and 24.0% in those aged 10-20 years. Over the entire age range cerebrovascular accidents accounted for 31.4% of all new registrations, and malignancies for 19.6%. Cancers of the oropharynx and oesophagus, which cause obstructive problems in the upper gastrointestinal tract were responsible for the vast majority of the cancers (16.8%).

### 3.6 Diagnoses of registered adult patients receiving HPN on 31st December 1998.

	Adults (n=284) %	Children (n=64) %	Total (n=348) %
Crohn's disease	39.8	3.1	33.0
Pseudoobstruction (motility disorders)	10.2	17.2	11.5
Vascular disease: ischaemic	6.7	0	5.5
thrombotic	3.2	0	2.6
Radiation enteritis	6.0	0	4.9
Intestinal volvulus	2.5	4.7	2.9
Malignancy (various types)	4.2	1.6	3.2
Scleroderma	3.9	0	3.2
Benign intestinal strictures	2.5	0	2.0
Ulcerative colitis	2.1	0	1.7
Idiopathic intractable diarrhoea	0	12.5	2.3
Autoimmune enteropathy	1.0	7.8	2.3
Microvillus inclusion disease	0	1.6	0.3
Post-necrotizing enterocolitis	0	1.6	0.3
Inborn error of metabolism	0	1.6	0.3
Liver disease	0	1.6	0.3
Cerebral palsy	0	1.6	0.3
Other gastrointestinal diseases	12.7	37.5	17.2
Other diseases	5.2	7.6	6.2
TOTAL	100	100	100

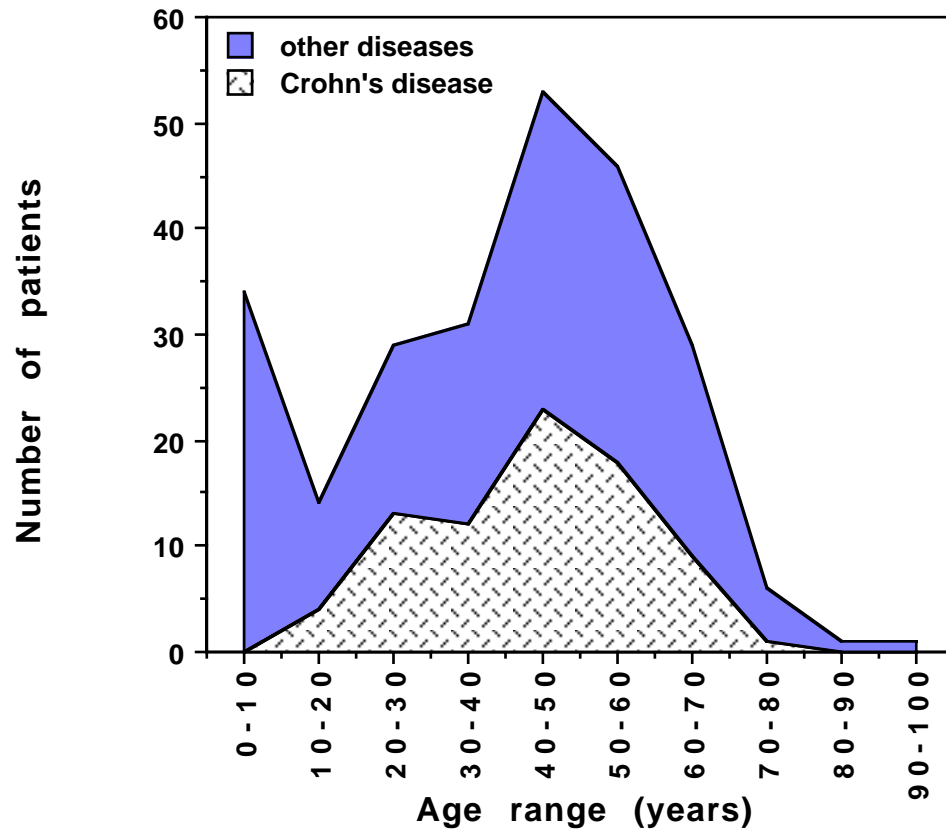
### **3.7 Diagnoses of registered adult patients receiving HPN on 31st December 1998**



**3.8 Diagnoses in registered patients starting HPN in 1998.** The diagnoses of patients starting HPN in 1998 (84 adults and 14 children; a total of 98) were broadly similar to those indicated above (sections 3.6 and 3.7). Crohn's disease accounted for 25.9% of all new registrations (33.3% in adults), pseudoobstruction for 5.6%, radiation enteritis for 2.8%, ischaemic vascular disease for 5.6%, and malignancy for 8.3%.

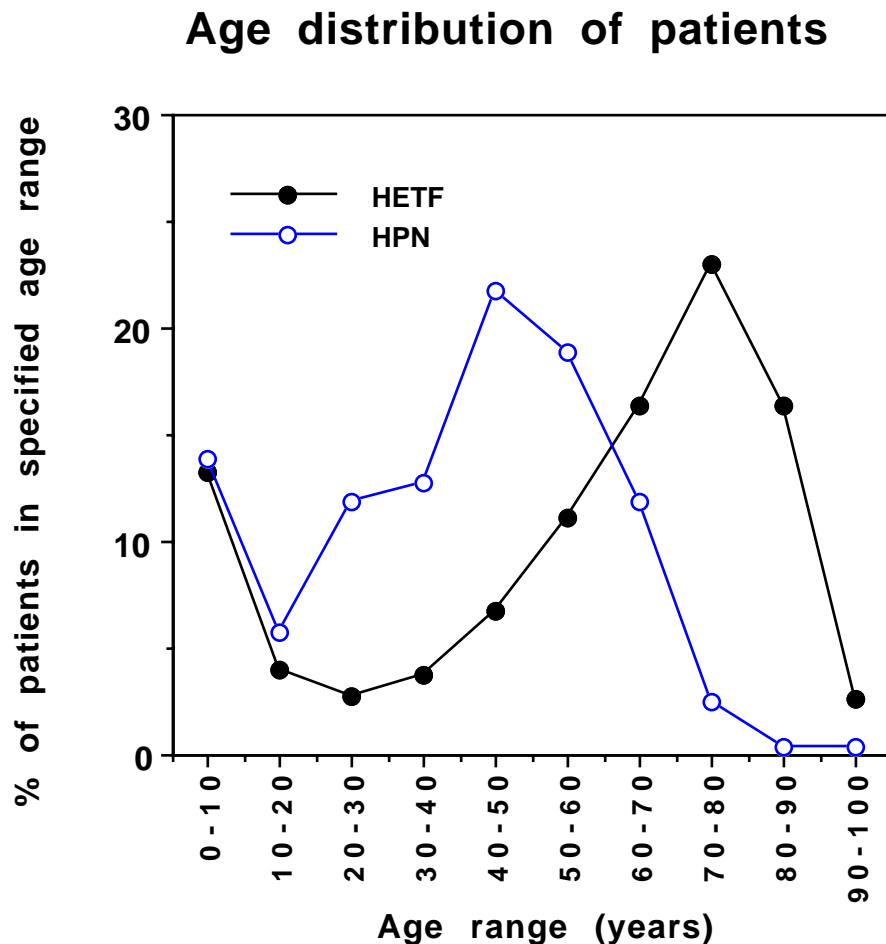
**3.9 Number of registered patients starting HPN between 1st January 1996 and 31st December 1998 according to age (80 patients with Crohn's disease, and 164 patients with other diseases; total n=244).**

**HPN: age distribution**



As for HETF, there was a bimodal age distribution. The most common age category for HPN was 40-50 years. This was heavily influenced by Crohn's disease.

**3.10 A comparison of the age distribution of registered patients receiving HETF and HPN between 1st Jan 1996 and 31st December 1998.**



A significant difference in age distribution was observed between the two groups of patients ( $p < 0.001$ , Chi-squared statistic). The most common age range for HPN was 40-50 years and for HETF, 70-80 years. Only 3.3% of patients on HPN were aged over 70 years compared to 42.0% of patients on HETF. In contrast, 47.3% of patients on HPN were aged 20-50 years compared to 13.3% in patients receiving HETF.

**3.11 Comment.** The commonest overall diagnosis in recipients of HPN was Crohn's disease (32.8% of all registrations). Other common diagnoses were motility disorders, vascular diseases affecting the gastrointestinal tract, radiation enteropathy and a heterogeneous group of intestinal diseases, which were particularly common in children.

## 4. REASONS FOR STARTING HANS IN ADULTS (>16 Y) AND CHILDREN (<16 Y)((1996-1998)

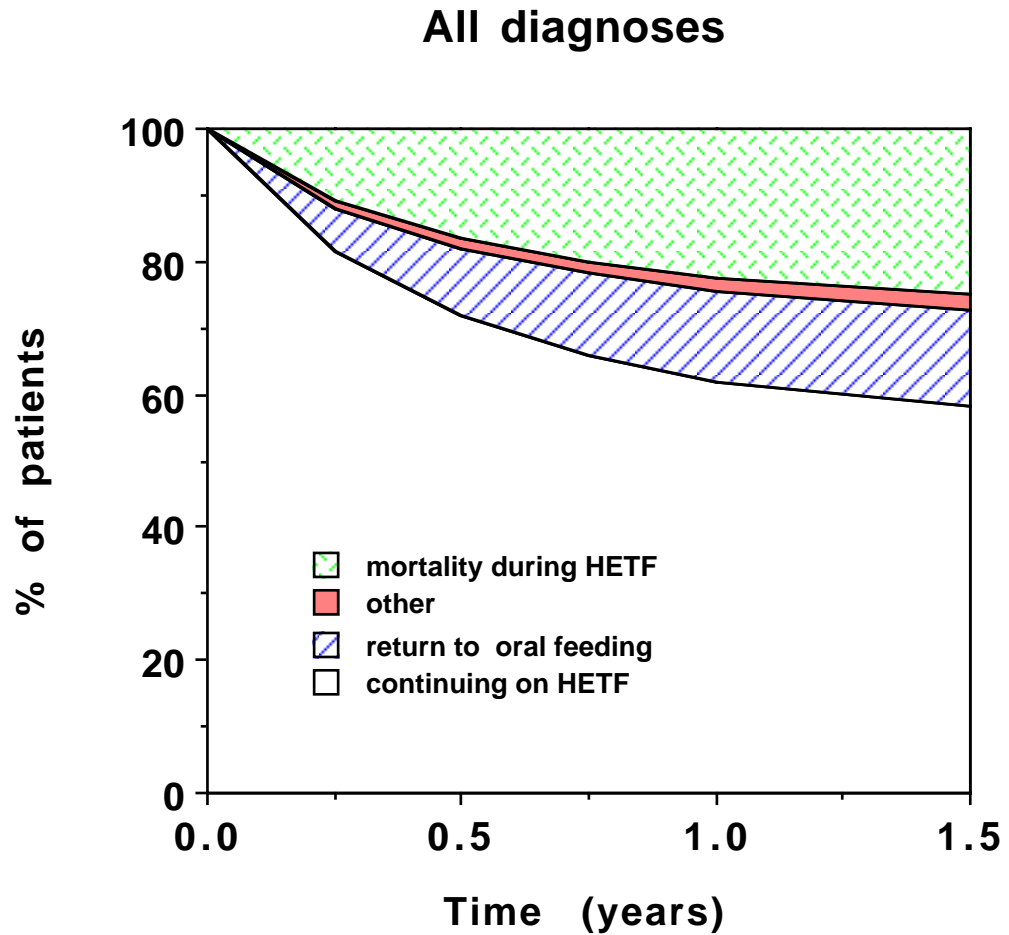
	Home enteral tube feeding		Home parenteral nutrition	
	Adults (n=12175) %	Children (n=2296) %	Adults (n=202) %	Children (n=42) %
Anorexia	4.6	4.4	0.0	0.0
Failure to thrive	1.1	44.6	2.0	7.1
Fistula	1.0	0.4	11.9	0.0
GIT obstruction	3.5	0.6	11.4	11.9
Malabsorption	1.3	3.7	21.8	31.0
Short bowel	0.4	1.2	39.5	38.0
Swallowing disorder	76.6	26.0	5.0	4.8
To improve ` nutritional status	9.6	15.9	8.4	4.8
Unpalatability of specialised feeds	0.2	1.5	0.0	0.0
Other	1.7	1.7	0.0	2.4

## 5. PATIENT STATUS AFTER STARTING HOME ENTERAL TUBE FEEDING (5.2 - 5.18) AND PARENTERAL NUTRITION (5.19 - 5.20)

**5.1** Reporters were asked to complete registration forms for patients starting HETF. They were also asked at six monthly intervals to provide an update on the status of all their patients at the same point in time. The information included mortality during HETF, continuing on HETF, withdrawal of HETF, refusal of HETF, and in patient admission in hospital at the time of the assessment. Dates of key events were also recorded, but no information was obtained after termination of HETF (e.g. after returning to full oral feeding). If the six monthly forms were not returned, outcome data could obviously not be assessed. This procedure is considered to be superior to the one used previously, in which reporters continuously reported key events as they happened. With the earlier procedure it was difficult to assess whether the absence of an update represented no change in clinical status, or failure to report a key event. The results that follow are the first BANS data on patient status after starting HETF (collected between 1997 and March 1999).



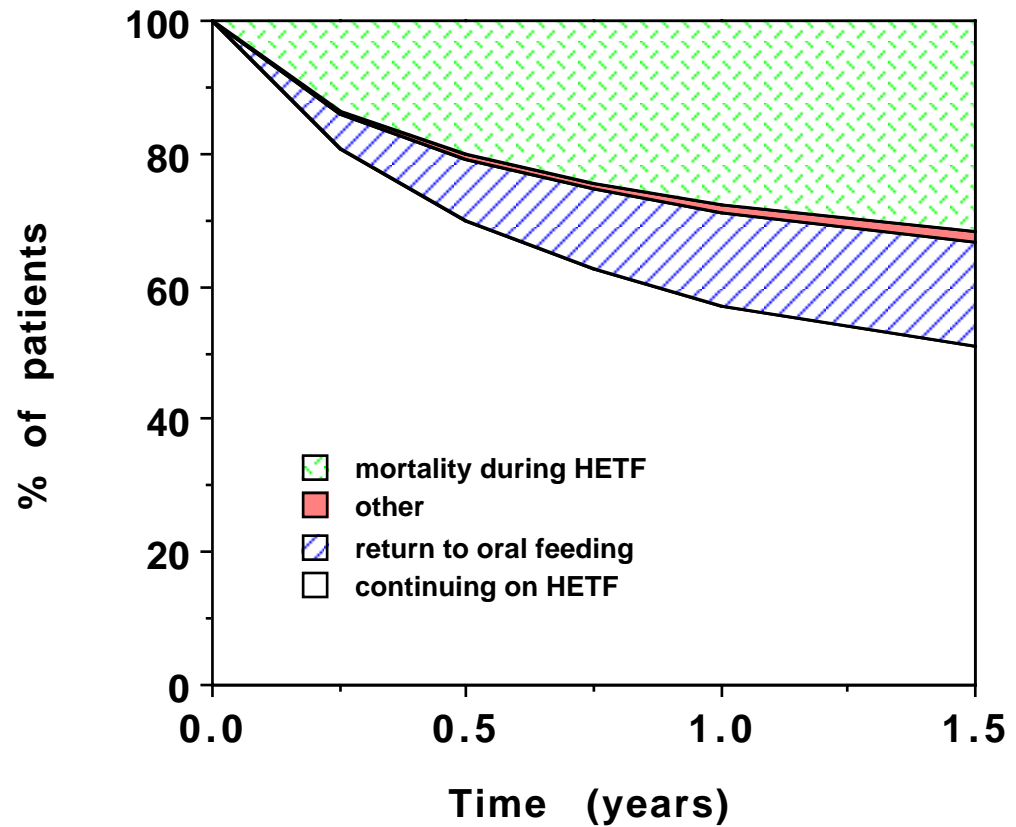
## 5.2 Patient status after starting HETF: all diagnoses (n=8832)



At one year after starting HETF: 22.4% died whilst receiving HETF  
 2.0% (other) withdrew/refused HETF (1.5%)  
 or were in hospital (0.5%)  
 13.6% returned to oral feeding  
 62.0% continued to receive HETF

### 5.3 Patient status after starting HETF: cerebrovascular accident (n=2466)

#### Cerebrovascular accident (all ages)



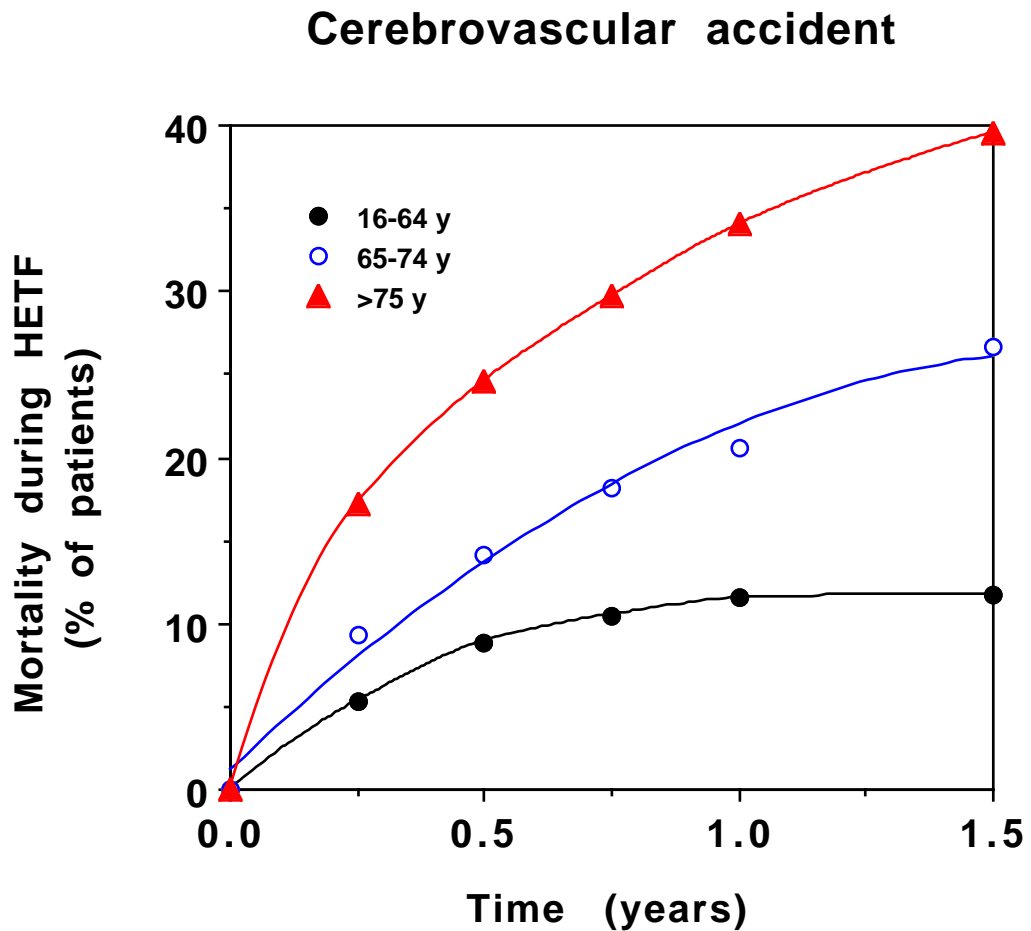
At one year after starting HETF: 27.8% died whilst receiving HETF (19.9% at 6 months)

1.1% (other) withdrew/refused HETF (0.9%) or were in hospital (0.3%)

13.9 % returned to oral feeding

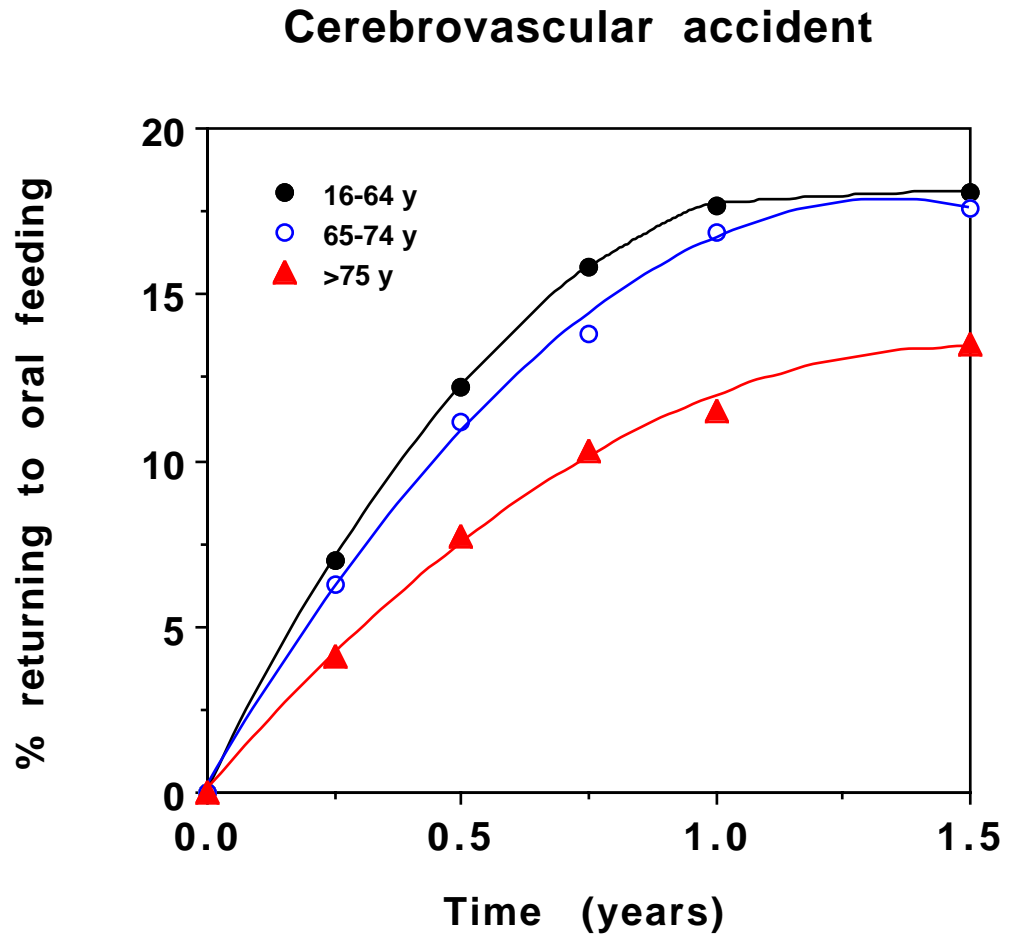
57.2% continued to receive HETF

#### 5.4 Patient status after starting HETF: effect of age on mortality during HETF in patients who suffered cerebrovascular accidents



When patients starting HETF were divided into three age groups (16-64 y, n=302 initially; 65-74 y, n=623; and >75 y, n=1525), there was a trend towards greater mortality ( $p < 0.001$  Chi squared for trend - using actual numbers of patients).and less likelihood of returning to oral feeding with increasing age (see section 5.5)

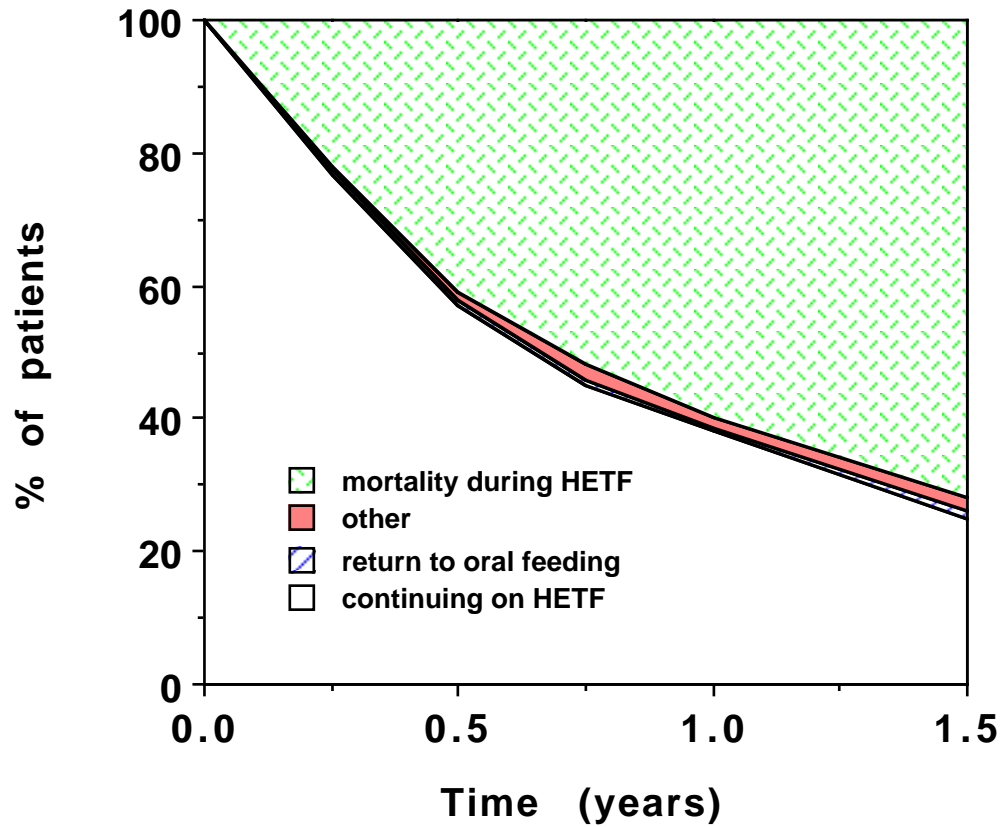
#### 5.5 Patient status after starting HETF: Percent of patients with cerebrovascular accidents returning to full oral feeding



The number of patients in each age category are the same as in fig 5.4

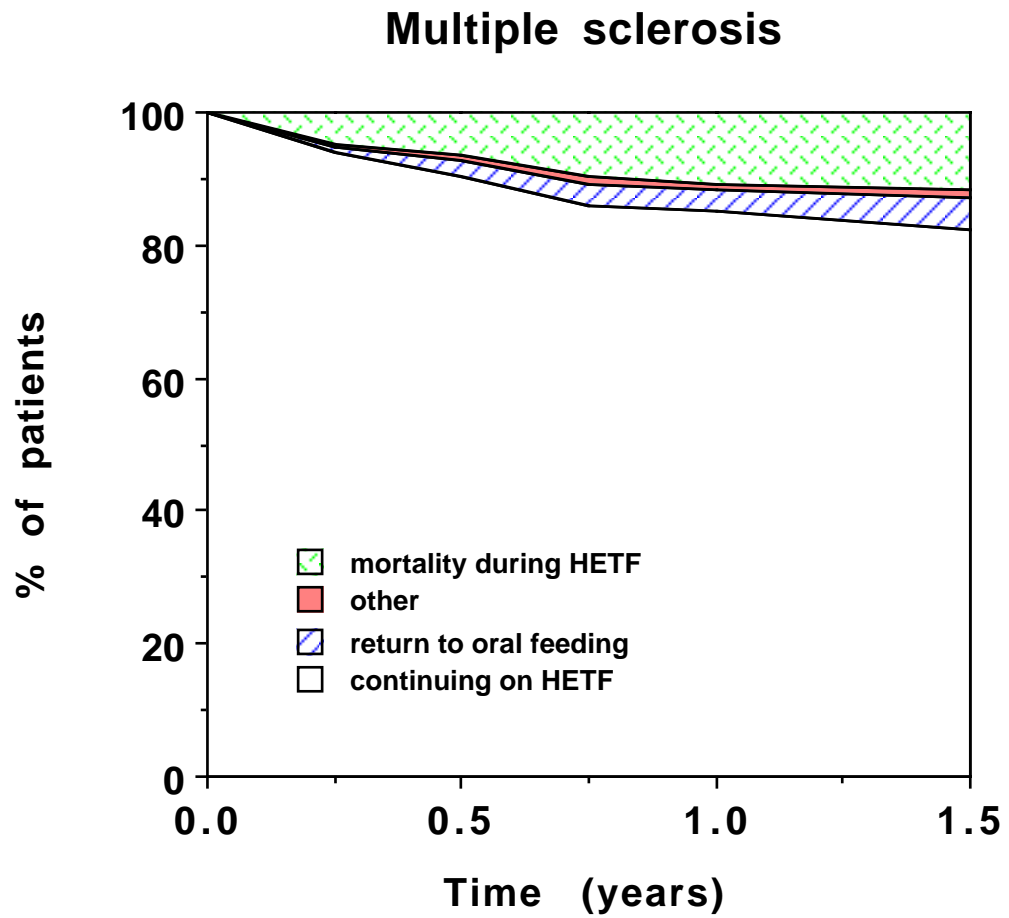
### 5.6 Patient status after starting HETF: motor neurone disease (n=393)

## Motor neurone disease



At one year after starting HETF: 59.7% died whilst receiving HETF (40.8% at 6 months)  
 1.7% (other) withdrew/refused HETF (1.4%) or were in hospital (0.3%)  
 0.3% returned to oral feeding  
 38.3% continued to receive HETF

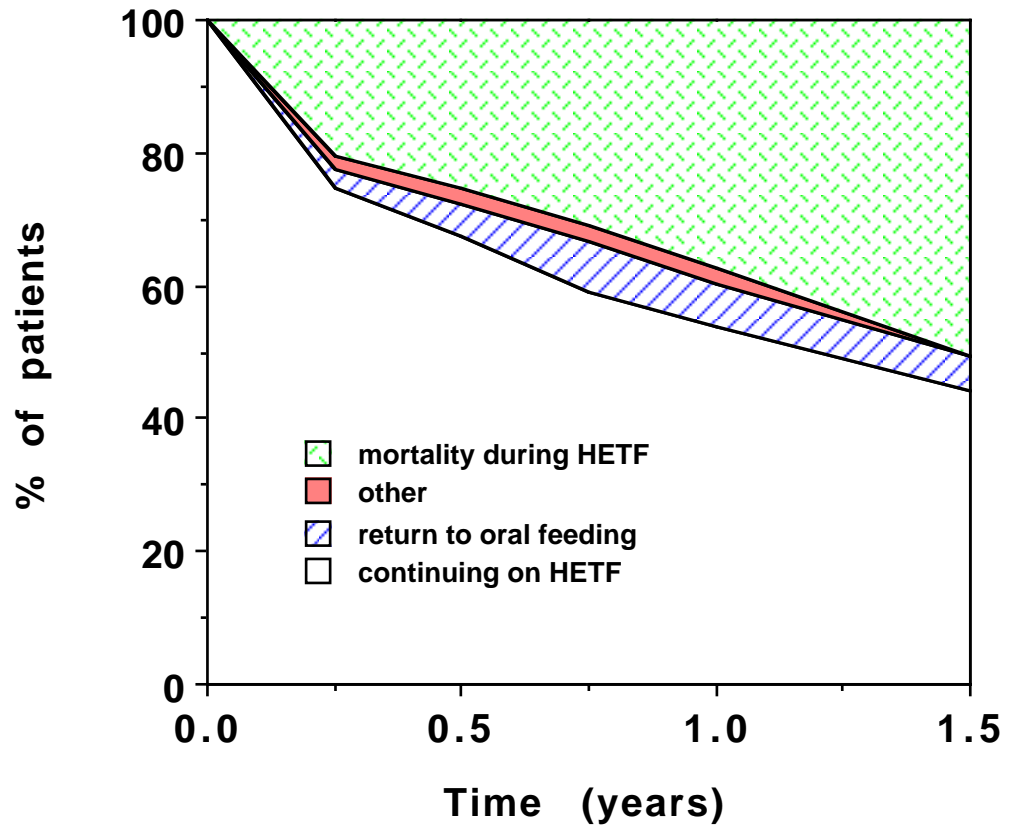
### 5.7 Patient status after starting HETF: multiple sclerosis (n=369)



At one year after starting HETF: 11.0% died whilst receiving HETF  
 0.6% (other) withdrew/refused HETF (1.4%)  
 or were in hospital (0.3%)  
 3.4% returned to oral feeding  
 85.0% continued to receive HETF

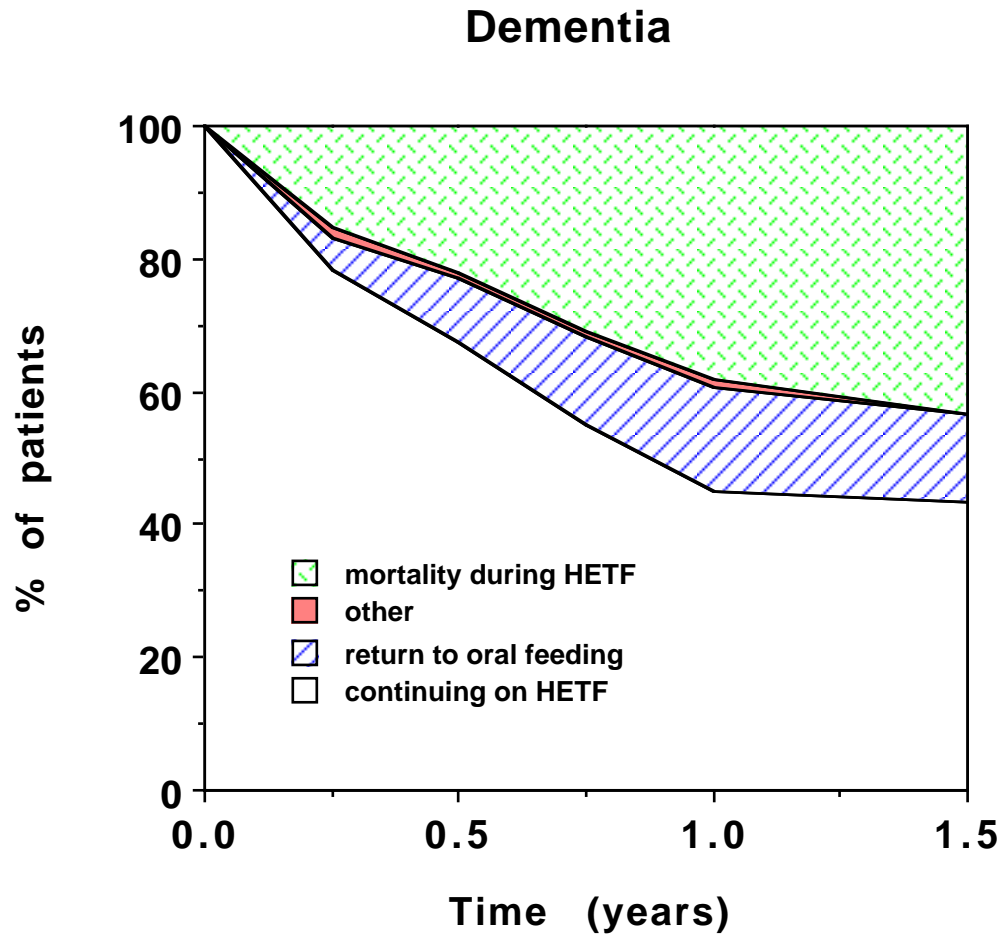
### 5.8 Patient status after starting HETF: Parkinson's disease (n=143)

## Parkinson's disease



At one year after starting HETF: 37.4% died whilst receiving HETF  
 2.2% (other) withdrew/refused HETF (2.2%)  
 or were in hospital (0%)  
 6.6% returned to oral feeding  
 53.8% continued to receive HETF

### 5.9 Patient status after starting HETF: dementia (n=129)

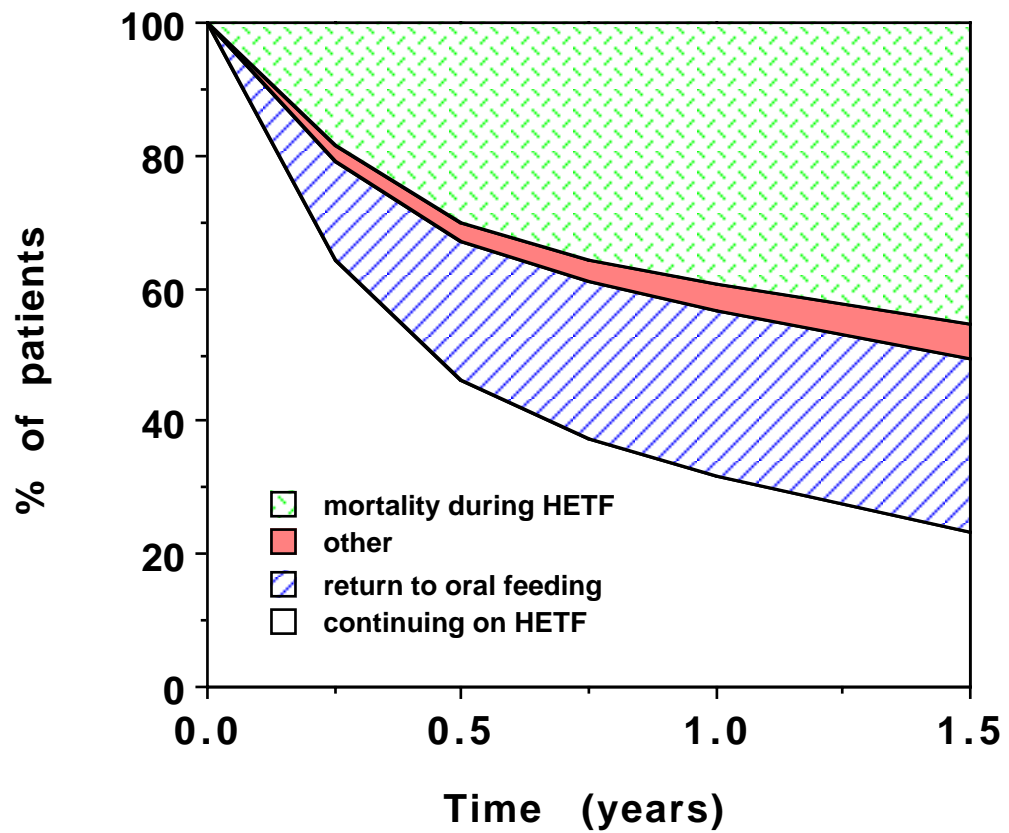


At one year after starting HETF: 38.0% died whilst receiving HETF  
 1.4 % (other) withdrew/refused HETF (1.4%)  
 or were in hospital (0%)  
 15.5% returned to oral feeding  
 45.1% continued to receive HETF

#### 5.10 Patient status after starting HETF: oesophageal cancer (n=1086)



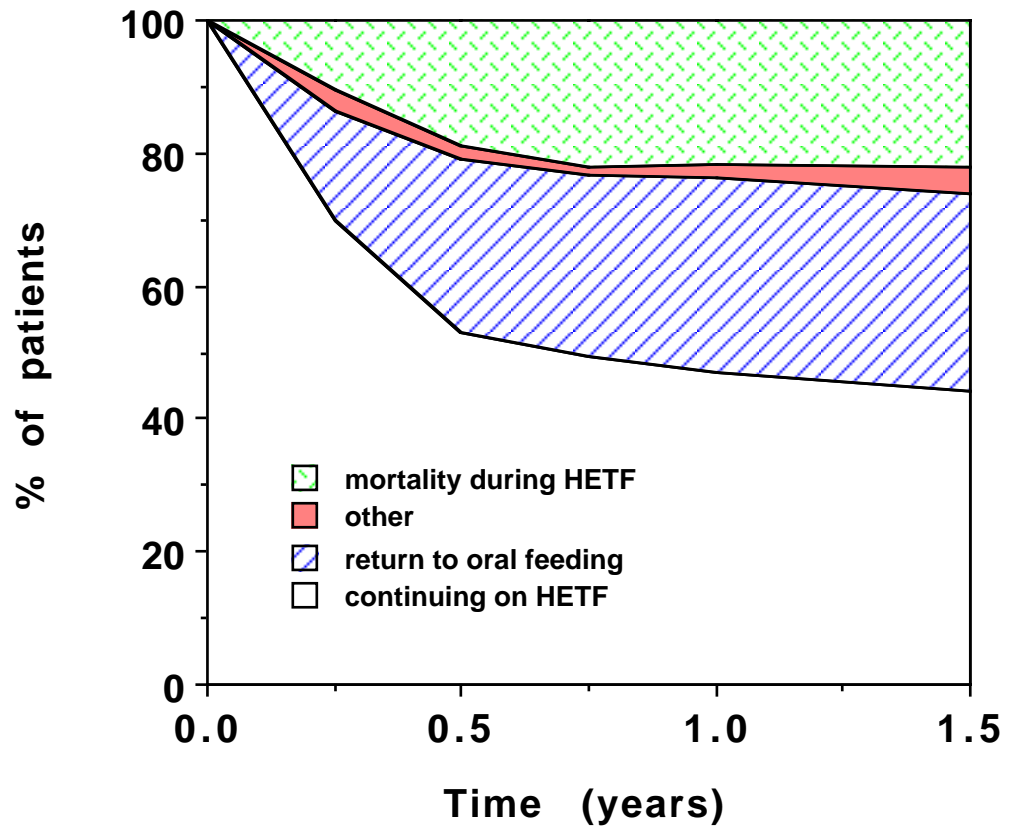
## Cancer: oesophageal



At one year after starting HETF: 39.5% died whilst receiving HETF (30.1 at 6 months)  
 3.7% (other) withdrew/refused HETF (2.5%)  
 or were in hospital (1.2%)  
 25.1% returned to oral feeding  
 31.7% continued to receive HETF

### 5.11 Patient status after starting HETF: oropharyngeal cancer (n=188)

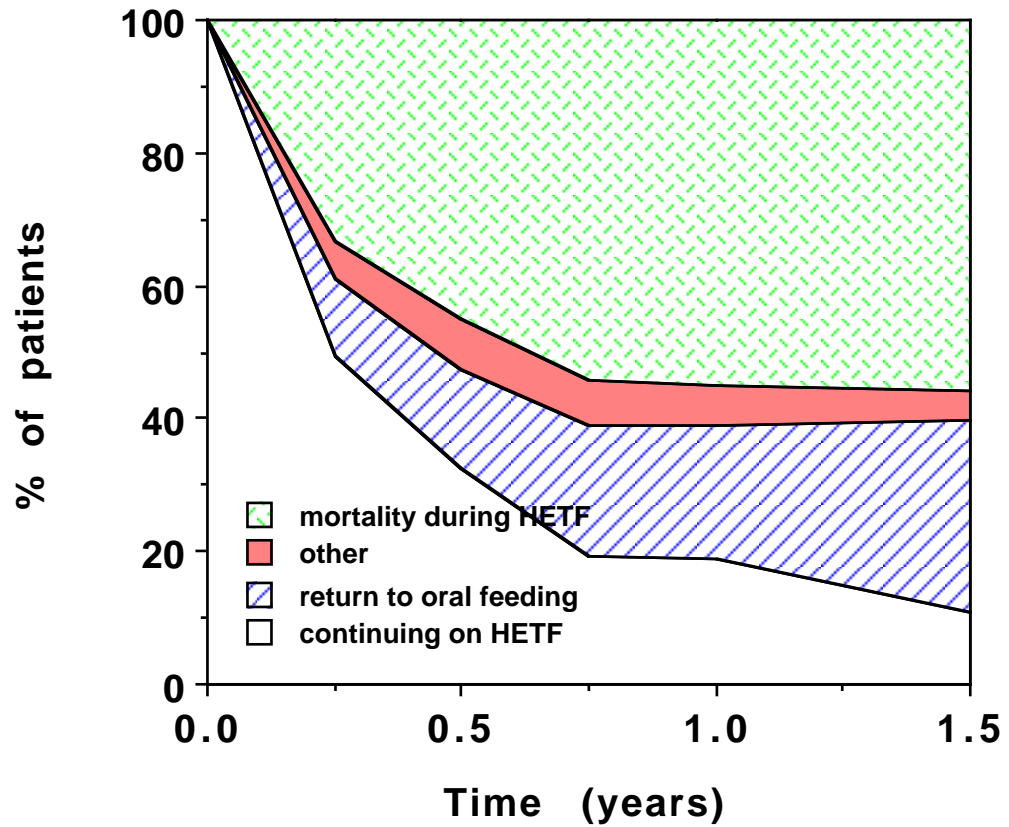
## Cancer: oropharyngeal



At one year after starting HETF: 21.6% died whilst receiving HETF  
 2.0% (other) withdrew/refused HETF (0.6%)  
 or were in hospital (0%)  
 29.4% returned to oral feeding  
 47.0% continued to receive HETF

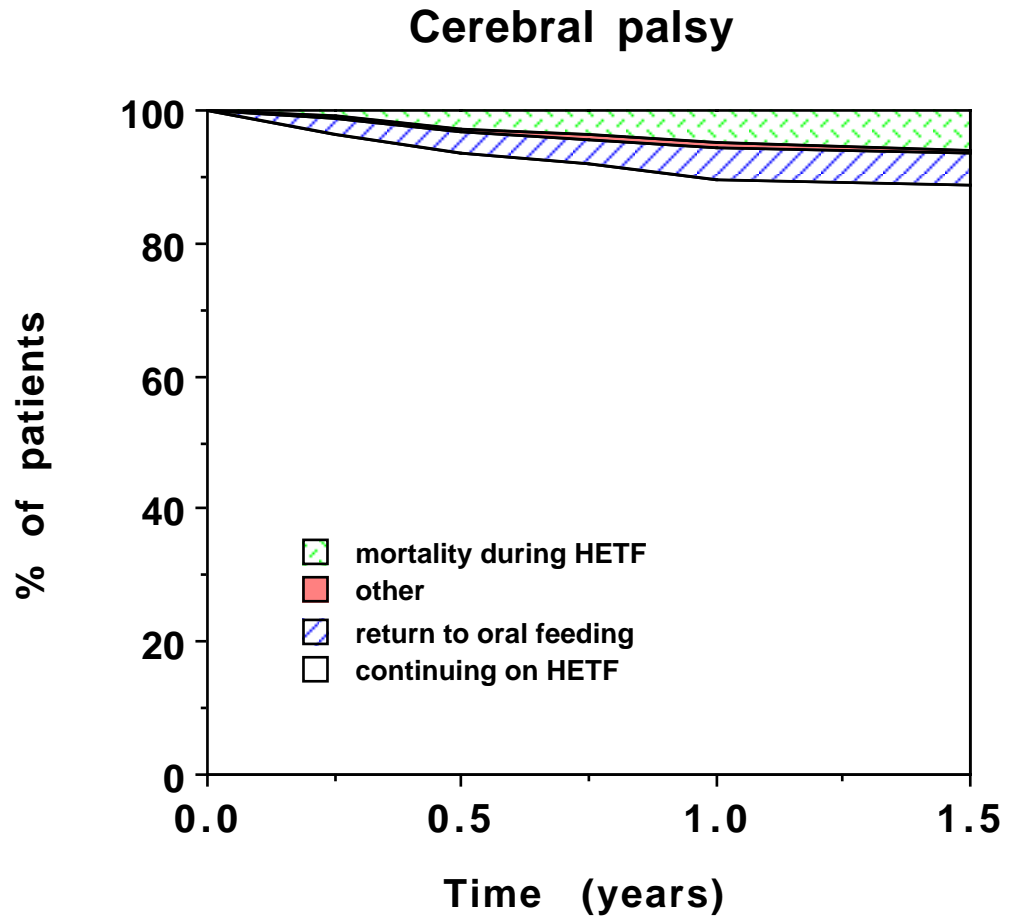
### 5.12 Patient status after starting HETF: gastric cancer (n=87)

### Cancer: gastric



At one year after starting HETF: 55.1% died whilst receiving HETF  
 5.8% (other) withdrew/refused HETF (5.8%)  
 or were in hospital (0%)  
 20.3% returned to oral feeding  
 18.8% continued to receive HETF

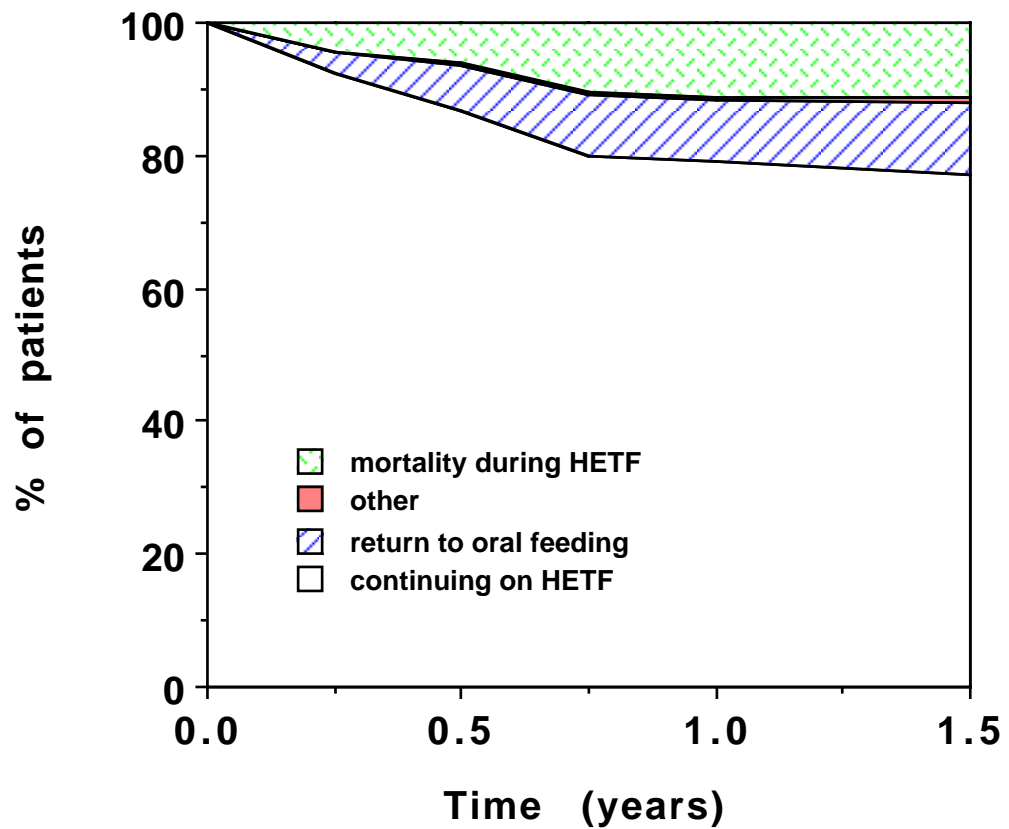
### 5.13 Patient status after starting HETF: cerebral palsy (n=451)



At one year after starting HETF: 5.0% died whilst receiving HETF  
 0.6% (other) withdrew/refused HETF (0.6%)  
 or were in hospital (0%)  
 4.7% returned to oral feeding  
 89.7% continued to receive HETF

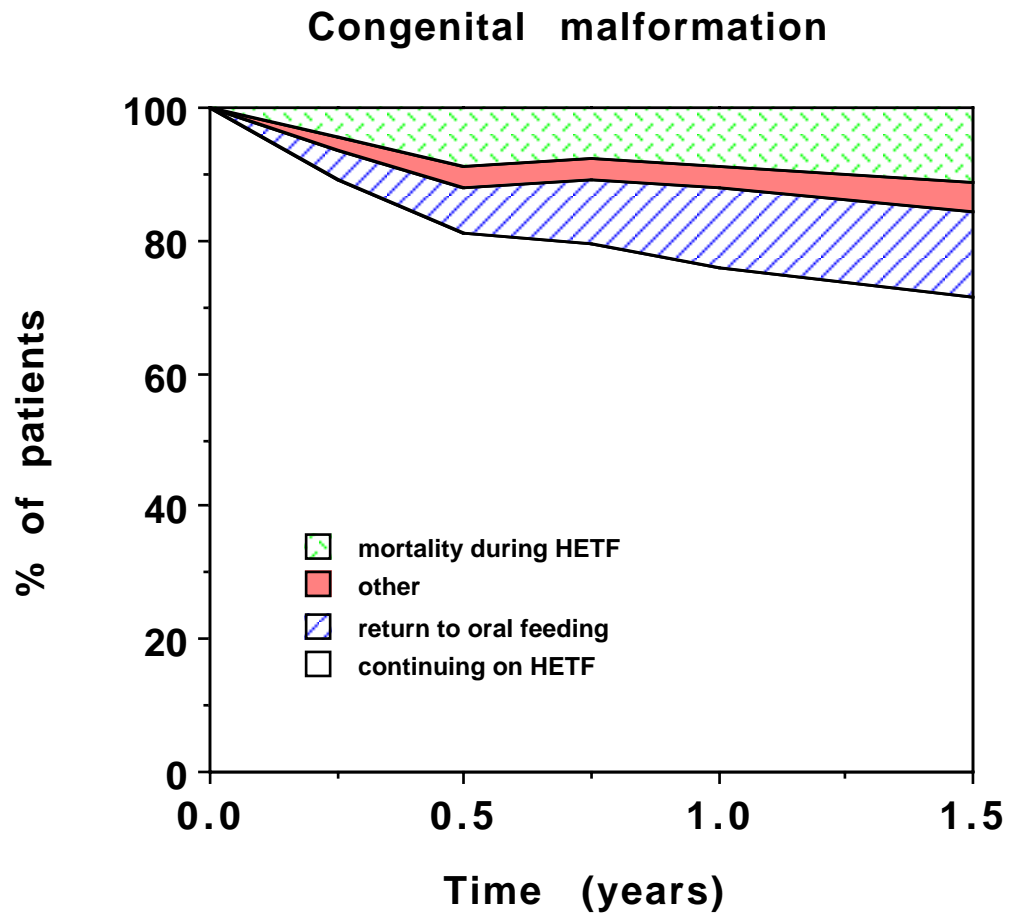
#### 5.14 Patient status after starting HETF: cerebral trauma (n=257)

## Cerebral trauma



At one year after starting HETF: 11.2% died whilst receiving HETF  
 0.5% (other) withdrew/refused HETF (0.5%)  
 or were in hospital (0%)  
 9.2% returned to oral feeding  
 79.1% continued to receive HETF

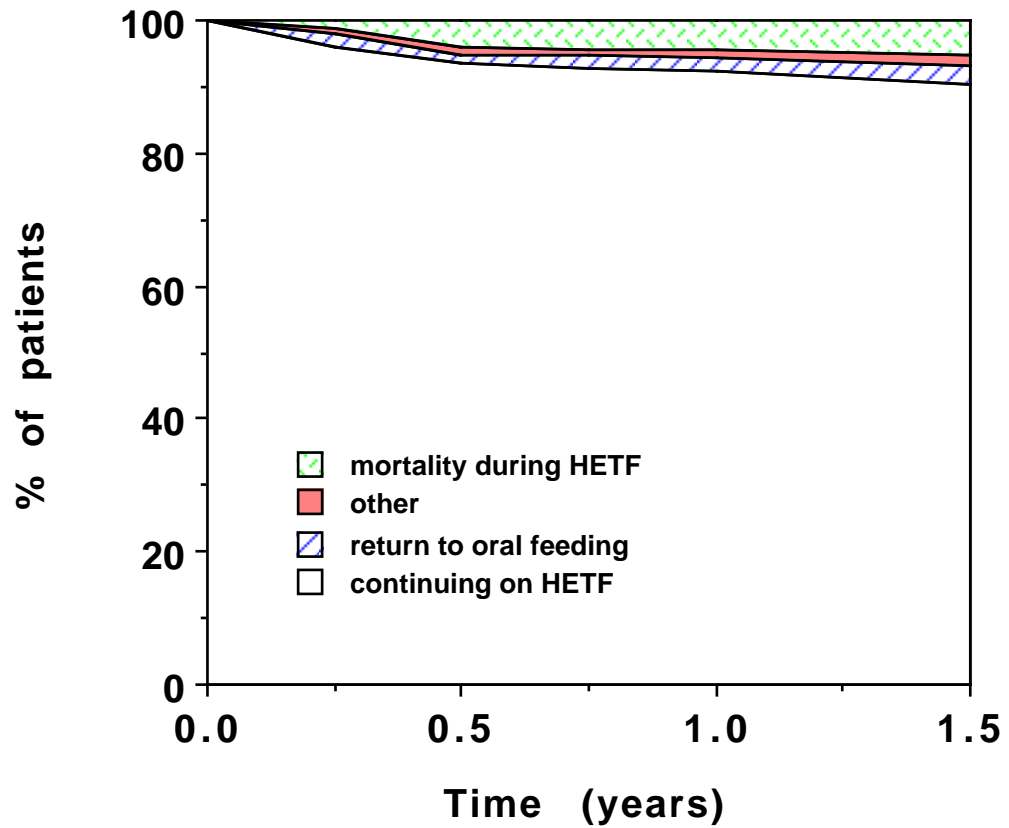
### 5.15 Patient status after starting HETF: congenital malformation (n=112)



At one year after starting HETF: 8.8% died whilst receiving HETF  
 3.3% (other) withdrew/refused HETF (1.1%)  
 or were in hospital(2.2%)  
 12.1% returned to oral feeding  
 75.8% continued to receive HETF

### 5.16 Patient status after starting HETF: congenital handicap (n= 281)

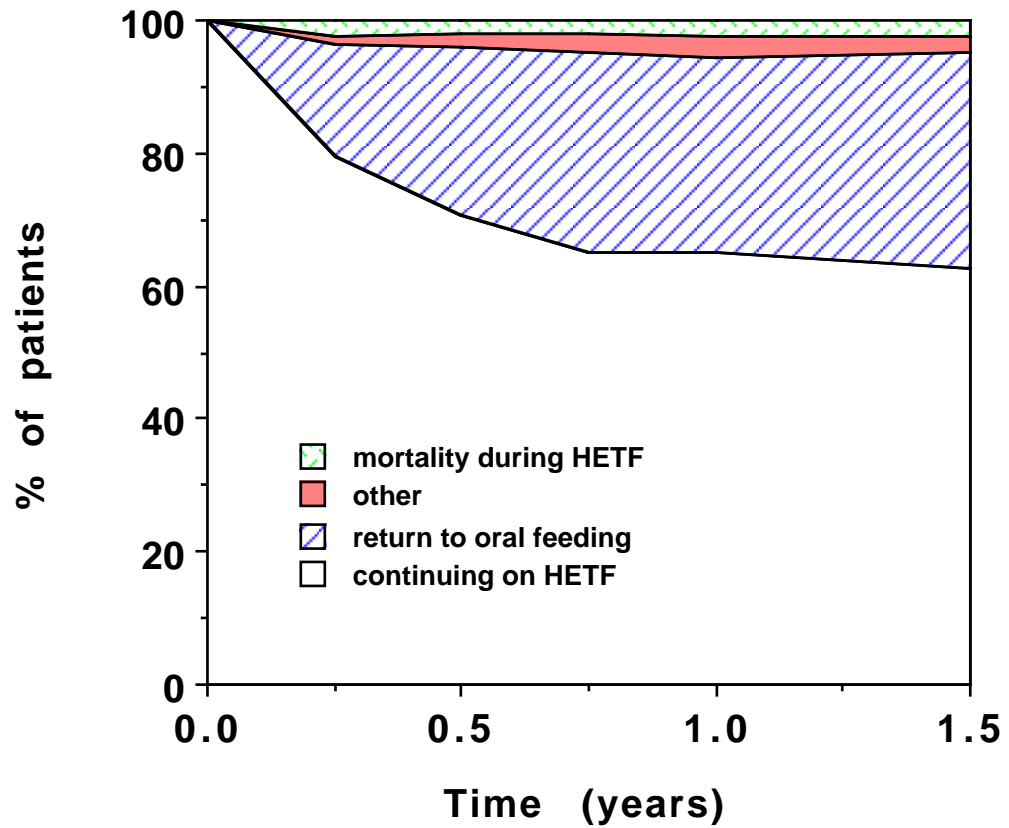
## Congenital handicap



At one year after starting HETF: 4.4% died whilst receiving HETF  
 1.3% (other) withdrew/refused HETF (0.9%)  
 or were in hospital(0.4%)  
 1.8 % returned to oral feeding  
 92.5% continued to receive HETF

### 5.17 Patient status after starting HETF: Crohn's disease (n= 216)

## Crohn's disease

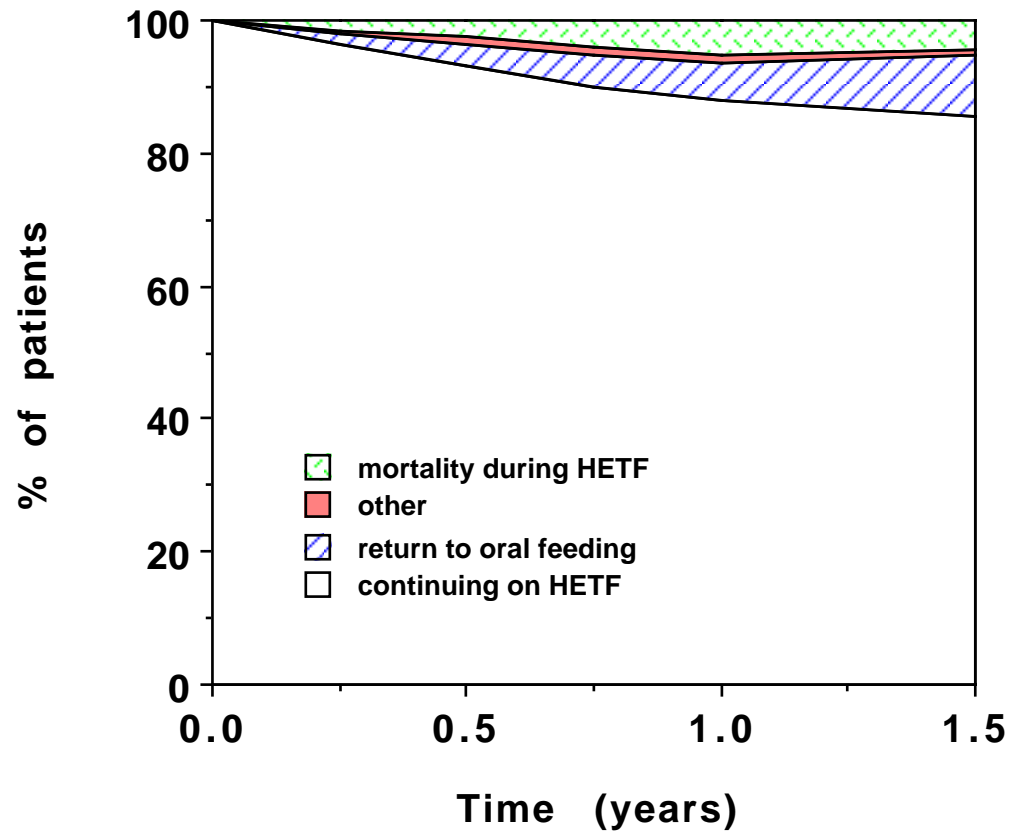


At one year after starting HETF: 2.3% died whilst receiving HETF  
 3.5% (other) withdrew/refused HETF (2.9%)  
 or were in hospital(0.6%)  
 29.1% returned to oral feeding  
 65.1% continued to receive HETF

### 5.18 Patient status after starting HETF: cystic fibrosis (n=324)



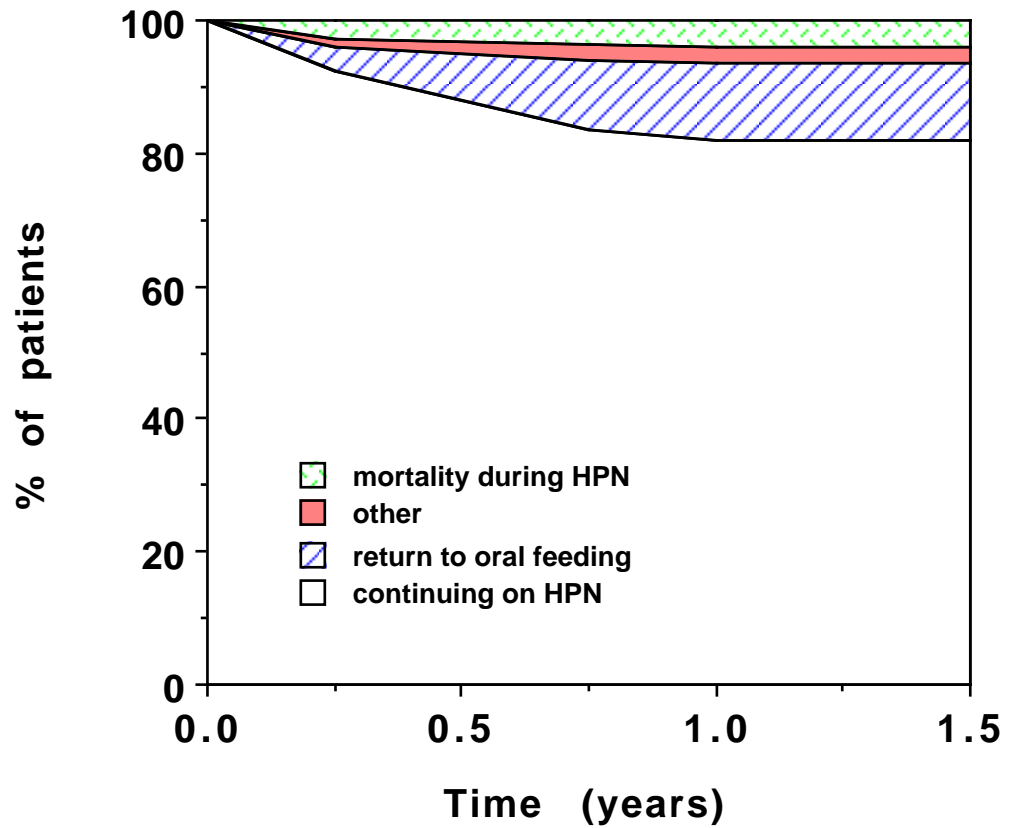
## Cystic fibrosis



At one year after starting HETF: 5.4% died whilst receiving HETF  
 1.1% (other) withdrew/refused HETF (0.7%)  
 or were in hospital(0.4%)  
 5.4% returned to oral feeding  
 88.1% continued to receive HETF

### 5.19 Patient status after starting HPN: all diagnoses (n=246)

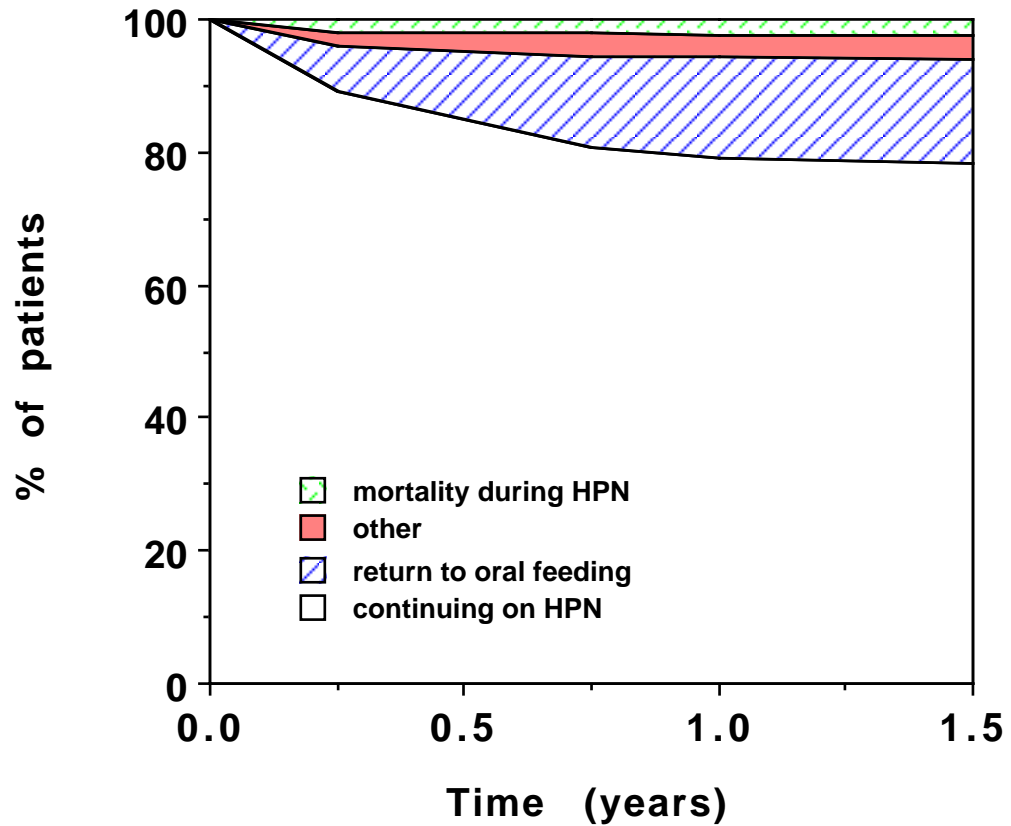
## All diagnoses



At one year after starting HPN: 4.0% died whilst receiving HPN  
 2.5% (other) withdrew/refused HPN (1.0%)  
 or were in hospital(1.5%)  
 11.4% returned to oral feeding  
 82.1% continued to receive HPN

### 15.20 Patient status after starting HPN: Crohn's disease (n=101)

## Crohn's disease



At one year after starting HPN:

- 2.4% died whilst receiving HPN
- 3.4% (other) withdrew/refused HPN (2.3%) or were in hospital(1.1%)
- 14.9% returned to oral feeding
- 79.3% continued to receive HPN

**5.21 Comment.** There was great variability in the outcomes of the heterogeneous groups of patients on HANS who differed widely in age, as well as type and stage of disease. For example the proportion of patients who continued to receive HETF one year after starting this treatment was found to be lowest (<50%) in patients with motor neurone disease, dementia, and oesophageal and gastric cancers (associated with a high mortality whilst on HETF ; 30-60%). It was intermediate (50-75%) in patients with cerebrovascular accident and Parkinson's disease (mortality whilst on

HETF; 25-50%), and highest (>75%) in patients with multiple sclerosis, cerebral palsy, cerebral trauma, congenital malformations and cystic fibrosis (mortality while on HETF, 2-12%). Furthermore, mortality during HANS was much lower in patients on HPN than HETF (4.0% versus 22.4% at one year).

The proportion of patients who returned to full oral feeding was also variable (0-30% by one year). In patients receiving HETF because of progressive neurological conditions, such as motor neurone disease, less than 1% returned to oral feeding by one year. In other more self-limiting or non-progressive neurological conditions the proportion was higher (e.g 13.9% at one year for patients who suffered a CVA). It is therefore important to monitor swallowing performance and encourage oral feeding when appropriate, so that unnecessary tube feeding is avoided. The quality and quantity of the diet should also be monitored to ensure adequate nutrient intake.

The mortality figures presented in this report should be considered as minimum values for overall mortality because they only take into account death during HANS. Patients who returning to full oral feeding, refused HANS (or in whom HANS was withdrawn for other reasons), may have died after termination of HANS, but this information was not obtained for practical reasons. The reported mortality was in almost all cases due to the underlying disease, rather than to incidental causes or complications of feeding (data not presented). Mortality and other outcome measures, such as returning to oral feeding, depend not only on diagnosis but also on the age of the patient, as demonstrated by patients with cerebrovascular accident. Those aged >75 years had a 3-4-fold greater mortality during HETF than those aged <65 years.

The proportion of time spent in hospital was generally small ( $\leq 1\%$  for HETF and  $< 2\%$  for HPN). This results in substantial cost savings to hospitals, but places more demands on carers in the community.