



# **A REPORT INTO THE CONSEQUENCES OF LIVING WITH POLIO FOR 63,500 YEARS**

**Peter Field**

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## **Contents**

- [Objective](#)
- [The Findings](#)
- [QUOTATIONS FROM SURVEY FORMS](#)
- [PRINCIPAL RESPONSES](#)
- [Method](#)
- [The Sample](#)
- [Circumstances at onset and now.](#)
- [Changes since recovery](#)
- [Analysis of changes since recovery](#)
- [Change in overall situation.](#)
- [Relationship of age at onset to probability of subsequent deterioration.](#)
- [SUMMARY OF FINDINGS](#)
- [Conclusion](#)

## **Objective**

This survey was conducted as a lay study into the impact on the lives of people who had polio earlier in life, and also to establish the frequency as well as the severity of the problems attributed to the "Late Effects of Polio".

The problems it has highlighted are shown to be common occurrences among those who had polio 30 plus years ago.

A worthwhile outcome to this investigation would be further, more clinical, investigation with a view to drawing up a list of good practices to minimise, if not to halt, the impact on those many polio survivors around the world.

## **The Findings**

**The true impact of the findings are not distorted by the statistics. The message is loud and clear - having had polio is likely to have a recognisable impact later in life. What form or extent this impact is likely to have cannot be measured or predicted - but that there will be an impact is clear for all to see.**

The survey is clear in its message that the medical profession are not familiar with the harmful effects that having had polio earlier in life are likely to have on the ageing body. They are inexperienced as to the probability of certain outcomes, which most likely leads to the dismissive attitude sometimes referred to. This, it is suspected, is a significant contributor to the trauma often described.

The production of the information sheet by the BPF for those who had polio earlier in life is confirmed as being a necessary and valuable aid to overcoming this shortfall in awareness. A condensed version of the statistical results of the survey may add weight where that is required. It is however recommended that attendant cautionary words are added clearly stating that the conditions described are not inevitable.

**It is a fact that the rising average age of the population will result in an increase in the age of polio survivors. The findings of this survey provide statistical evidence of a reduction in the physical capability of the individual polio survivor and the inevitable attendant increase in the severity of disablement - polio is not going to leave the UK scene for some time to come and is likely to have a significant impact on the demands on Care in the Community.**

## **QUOTATIONS FROM SURVEY FORMS**

The following are a sample of quotations extracted verbatim from the completed forms which in themselves paint perhaps the most important picture to emerge from the whole survey. A Doctor can hardly be expected to interpret a set of circumstances presented at one moment in time, particularly when change has in all probability taken months if not years to manifest itself with little or no clinical precedent or in many cases medical logic. They none the less express the feelings, findings and experiences of a cross section of the respondents. They have been analysed into the [summary of findings](#), such is their importance.

It is worth while pointing out that great emphasis was placed on these descriptive responses, setting aside the emotion that appeared in quite a few, they are the best measure of the overall impact on the lives of those who actually had polio. They are not dreamed up. They were not expressed in a medium which would elicit a sympathetic response. Many are factual reporting of a very real situation, most without question carry an important humanitarian message for the medical profession.

**Q1.** "Now that I have MS it's difficult to assess which may be late effects of polio or the MS" *Female, born 1957, polio at 9 months.*

**Q2.** " At 39 years (of age) a rapid decrease in mobility, an increase in fatigue, weakness and tiredness and now I have constant severe pain. Up to three years ago I never considered myself as having a disability.....I was always on the go.....so when this happened to me 3 years ago it was like a nightmare. I now cannot walk at all. I would never ever believe that I would deteriorate so rapidly and feel so ill as I do now". *Female, born 1953, polio at 2 1/2 years.*

**Q3.** "Condition static for 26 years, worse after fractured leg in 1982, much worse in last 18 months" *Male retired Doctor, born 1927, polio at 28 years*

**Q4.** "Diagnosed at National Hospital for Nervous Diseases (London) in 1989 as suffering from "Post polio

muscular atrophy" (LEP) Informed - no treatment, no cure, no prognosis! This was as a result of marked loss of muscle and range of movement during late 1980's. Initially told my muscles needed building up - therefore 3 years of physiotherapy, ( I did not accept this explanation as I had always been very physically active). Result of physio - increase loss of muscle power and range. Was told later I should have rested not exercised. Too late! Left me very frightened for the future, - will I end up with no use of either arm?" *Female, born 1947, polio at 18 months.*

**Q5.** "I felt as fit as a fiddle till I reached forty, My back and joints started to give me pain. By the time I was 43 I realised that I couldn't do half the things I had always taken for granted." *Female, born 1948, polio at 6 months.*

**Q6.** "Have horrendous tiredness/fatigue problems - for me the answer is to lie down for an hour at least to let the body recover. I dread the cold." *Female, born 1945, polio at 4 years.*

**Q7.** "Recovery was so good I was able to become a District Nurse, with all that entails. In 1986 I was visiting a client and found I couldn't negotiate the outside path and steps without arm support. Subsequent neurological investigation revealed LEP. My strength has deteriorated to the extent that I had to retire completely last year after having gone on part time and then changing career completely." *Female, born 1941, polio at 20 months.*

**Q8.** "I find exhaustion is a problem - acute tiredness - it's awful - functioning but feeling only half alive. I can go to bed feeling "alive" and wake up feeling so very heavy and awful. My shoulders are now giving great concern - they have had enough of being used as hips, and my arms are tired of being used as legs." *Female, born 1946, polio at 6 yrs.*

**Q9.** "This extreme fatigue is what worries me most" *Female, born 1925, polio at 26.*

**Q10.** "I have been unable to get downstairs for 8 years, only twice lately when I had to slide down each step on my behind, but I couldn't get back up again so had to call an ambulance to get me up into a chair. My social worker has put in for a stair lift for me a long time ago. But they say there is a long waiting list." *Female, born 1926, polio at 16 months.*

**Q11.** "Noticed weakness in legs after major operation for gall bladder removal 10 years ago. Now I get tired and unable to walk outside without escort. Stairs and steps I cannot manage." *Female, born 1920, polio at 7 years.*

**Q12.** "I feel I am fortunate to have held fairly steady physically - long may it last, I couldn't afford to loose a lot! If I have an illness - flu cold etc., it takes a long time for me to get back to normal" *Female, born 1939, polio at 17 years.*

**Q13.** "I find gentle activity is more beneficial than staying in bed or inactive which only increases pain. Painkillers taken every day seem to increase problems." *Female, born 1939, polio at 12 years.*

**Q14.** "I worked hard in a large house and did get excessively tired and crotchety and had much shoulder, elbow and knee problems (crutches) - but now in retirement using a chair - and no one else to worry about, I can pace myself, rest when I feel like it and feel I'm a much calmer, nicer person. If only the great value of rest at regular intervals was stressed in rehabilitation to ones relatives as well perhaps the value of wheelchairs suggested, I might have enjoyed life more." *Female, born 1927, polio at 25.*

**Q15.** "After reading in the newspaper the late effects of polio, I could think of many things over the last 30 years, many falls also the feeling of desperate tiredness.....my GP always said it was old age." *Female,*

*born 1920, polio at 1 year.*

**Q16.** "I improved quite well until 7 years ago when I had a flu like attack, since then my walking has deteriorated very badly." *Female, born 1929, polio at 28.*

**Q17.** "In 1982 at age 54 I had, quite suddenly, very severe Thyrotoxicosis. After this my muscle power diminished so much I could not recover my strength and need a powered scooter to go anywhere except around the house." *Female, born 1927, polio at 18 years.*

**Q18.** "About 2 1/2 years ago I started to become very tired and fatigued, and had a small lump on the left side of my jawbone, which was not painful. After 8 months and three biopsies later I was told I had an illness called Histiocytosis X. I asked if this was anything to do with having had polio: was told definitely not. Reading your bulletin last year on post polio syndrome I've been getting all those symptoms so I was surprised to be told polio had nothing to do with it." *Male, born 1950, polio at 3 years.*

**Q19.** "Condition deteriorated markedly so in 1988; markedly indeed since 1992.

- 10 years ago could walk 5 miles
- 5 years ago could walk 2 miles
- 1 year ago could walk 300 yards
- now can walk 100 yards.
- 10 years ago could manage 5 flights of stairs
- now can manage only one.

The orthopaedic problems are bad enough; the systematic exhaustion is harder to predict and thus to compensate for" *Male, retired doctor, born 1942, polio 8 years.*

**Q20.** "I did recover from it (polio) to the extent that for several years I was a heavy goods vehicle driver, doing long distance work. But now the only use I have in my right arm is the wrist and fingers." *Male, born 1940, polio at 5 years.*

**Q21.** "I am at odds with the medical profession. I maintain that my troubles are connected with polio, particularly LEP, but hospital state the cause is spinal stenosis." *Male, born 1932, polio at 20 years.*

**Q22.** "As well as polio I have developed MS since 1977 after my third child. I have arthritis in most of my joints and I have bronchial asthma." *Female, born 1946, polio at 18 months.*

**Q23.** "The LEP was more noticeable from four years ago when I had a bad fall. I spent three weeks resting in hospital and never got back to the previous mobility (as before the fall)." *Male, born 1931, polio at 14 years.*

**Q24.** "The GP treatment of polio patients leaves a lot to be desired.....it is time to respectfully ignore BMA opinions!!!! There are many polio persons who are not BPF members consistently deriving benefit from Chiropractic treatment." *Male, born 1931, polio at 11 years.*

**Q25.** "By the time I was 16 I was in full time employment in the engineering trade. In robust health and stronger than most boys of my age. This trend continued until I was 32 when through the effects of polio the part of my central nervous system that controls the breathing deteriorated.....I require a respirator to live.....(apart from my breathing) I consider my condition at the age of 64 as good as most people, only my breathing holds me back." *Male, born 1930, polio at 7 years.*

**Q26.** "I think I may be following the general pattern of 'LEP', loss of strength, weakness and fatigue over the past 18 years which brings on such frustration when you look back and think of what you were once capable of doing without pain even though it was limited." *Male, born 1928, polio at 17 years.*

**Q27.** In response to the question as to whether the disability has changed "Yes, whole body now diagnosed by hospital as post polio syndrome." *Male, born 1921, polio at 36 years.*

**Q28.** "Retired from work at age of 60 - found journey to work exhausting. Last six years have needed ventilator at nights to clear blood gases." *Male, born 1921, polio at 31 years, was on respirator.*

**Q29.** "By my late teens I had reached 80% normal physical ability. At this stage I had no need for any aids and I led a normal active life until I reached my late thirties, when there began a marked and rapid deterioration in my condition for no apparent reason. There was no medical reason for this until I discovered the condition of post polio syndrome. I continued to deteriorate and would not be able to function without the constant aid of my wife and mobility aids. I would consider that my capabilities are now about 30% and still falling." *Male, born 1942, polio at 3 years, was on respirator.*

## PRINCIPAL RESPONSES

DESCRIPTION	NUMBER	PERCENT
HOSPITALISED FOR OVER ONE MONTH AT ONSET	917	79%
HAS NOTICED DETERIORATION SINCE RECOVERY	895	77%
REPORTED LOW STAMINA/HIGH FATIGUE	774	66%
REQUIRES MORE HELP NOW FOR DAY TO DAY TASKS	702	60%
GENERAL WEAKNESS	671	57%
USES WHEELCHAIR ON REGULAR BASIS	652	56%
USES WALKING STICKS	491	42%
USES CALIPERS ON ONE OR BOTH LEGS	425	36%
HAD TO LEAVE WORK DUE TO WEAKNESS	364	31%
ATTENDS ORTHOPEADIC HOSPITAL	321	28%
GENERAL PAIN	313	27%
IS UNDER REGULAR TREATMENT BY GP	274	23%
WAS ON RESPIRATOR AT ONSET (OR NOW)	225	19%
BREATHING DIFFICULTY	189	16%
HAS SCOLIOSIS	195	17%
USES CRUTCHES, SHOULDER OR ELBOW	190	16%
HAD TO LEAVE WORK DUE TO PAIN	187	16%
ARM/SHOULDER PROBLEMS DUE TO USING CRUTCHES	185	16%
HAS DEVELOPED ARTHRITIS	181	16%
HAS HAD GENERAL SURGERY	178	15%
REPORTED POOR BALANCE	174	15%
ATTENDS GENERAL HOSPITAL	172	15%

ATTENDS SPECIAL UNIT	109	9%
FEELS THE COLD	78	7%
ATTENDS PAIN CLINIC	62	5%
REPORTED P&N HANDS	59	5%
REPORTED HEART PROBLEM	51	4%
HAS OSTEOPOROSIS	47	4%
ATTENDS REHABILITATION UNIT	44	4%
MENTIONED ME/MYASTHENIA GRAVIS	8	1%
<b>TOTAL SURVEY FORMS</b>	<b>1167</b>	

## Method

The statistics were compiled from the returns of all those who responded to a random mailing of questionnaires in the BPF magazine and some that were handed out at rehabilitation centres. It was not an easy questionnaire to complete, covering as it did aspects of pain and sleep, in addition to the main questions related to the residual effects of the polio.

Quite obviously without a progressive and standard measure of muscle power over the years it is not possible to paint a true picture of the impact of ageing on such a large number of people. The survey results are non the less a view of how the respondents have lived, and are continuing to live with the after effects.

The purpose of the survey was to establish if changes do take place, if there is any consistency as to the type changes that are being experienced, and what the most common changes are.

The survey tried to avoid leading questions, in so doing some information has undoubtedly been left out. It also proved impossible for many to give details of the state of recovery immediately after the onset simply as they were so young at the time. However it was possible to reconstruct some of the missing data by reading the responses carefully.

Only 45 forms out of the 1220 returned were unusable in the statistical review, which is a very commendable result. Only eight were unusable for the date of birth and age at onset review.

## The Sample

Survey forms were returned by 1212 people with an average age of 60.1 years. Of the 1212, 782 or 65% female and 430 or 35% male. The age of the respondents shows that only 29% of the males were born before 1939 as opposed to 37% of the women, in fact only 7 men were over the age of 80 as opposed to 36 women. This trend surprisingly evens out at the end with the average age of all the females at 60.4 years and 59.6 years for the men. Finally the years since onset provide some remarkable figures as to the longevity of ex polio's. Of all the respondents, 674 or 56% are this year over 60 years of age. This endorses what has been said about polio not going away for some time to come.

	<i>BIRTH</i>		<i>ONSET</i>	
	<i>No</i>	<i>%</i>	<i>No</i>	<i>%</i>
<i>1909 to 1914</i>	84	7%	43	4%

1915 to 1924	265	22%	122	10%
1925 to 1934	308	25%	148	12%
1935 to 1944	216	18%	193	16%
1945 to 1954	288	24%	484	40%
1955 to 1985	51	4%	222	18%
TOTAL	1212		1212	

Fig 1. Gives the number of births in ten year brackets, together with the number of cases of polio infection in the same years

It must be born in mind when looking for significant trends that these figures are of survivors not total cases, it follows that they cannot reflect the average situation during any one period. This is also true of the seriousness of cases in so much as it would be reasonable to assume that the more seriously effected would have enjoyed less chance of survival during the earlier part of the century.

	AGE AT ONSET	
YEARS	No	%
UP TO 1	173	14%
1 TO 3	353	29%
4 TO 6	177	15%
7 TO 12	164	14%
13 TO 20	129	11%
21 TO 30	170	14%
31 UP	46	4%
TOTAL	1212	

Fig 2. Is the age of respondents at the time they contracted polio

The age at onset is recorded in [Fig. 2](#), but shows no significant variance between the sexes.

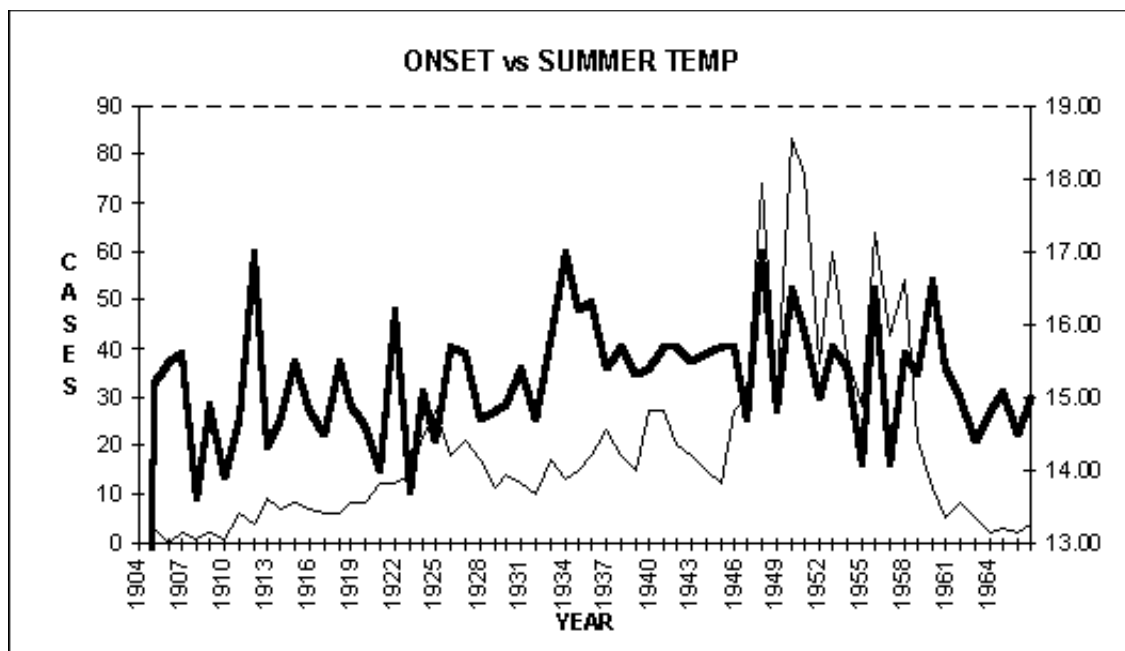


Fig 3. Shows the number of cases per year, with the average summer temp shown in the heavier line.

The date of onset is of some academic interest if only because it confirms the relationship between the number of cases and the average peak daily temperature during June, July and August each year. Hot summers contributed to a rise in the number of polio cases. The earlier information is obviously less dramatic, but the pattern in the late forties is very clear with the number of cases rising with peaks in summer temperatures as shown in [figure 3](#).

Reverting to the question of age and its relevance to the following information, the evidence is that there is very little, if any, significance between the sexes or the age at which polio was acquired.

	AVERAGE AGE/YEARS FROM ONSET			
	No	%	AVE/AGE	FROM ONSET
MALE	430	35%	59.57	50.81
FEMALE	782	65%	60.39	53.36
ALL	1212		60.14	52.45

Fig 4. Male/Female, age and years from onset

In keeping with the previous statistics [Fig 4](#), shows that the average age of the female respondents was slightly greater than the males, they also had polio at a marginally earlier average age. However it is felt that the difference between the statistics for the sexes again indicates that there is no significant difference, or at least not sufficient difference to warrant recording in the results.

		YEARS SINCE ONSET					
	MALE	%	FEMALE	%	ALL	%	
80 PLUS	7	2%	36	5%	43	4%	
70 TO 79	35	8%	87	11%	122	10%	
60 TO 69	51	12%	97	12%	148	12%	
50 TO 59	67	16%	126	16%	193	16%	
40 TO 49	180	42%	304	39%	484	40%	



30 TO 39	90	21%	132	17%	222	18%
TOTAL	430		782		1212	

Fig 5. *Details of years since onset by sexes and total*

This feature is brought about by the higher percentage of onset in the 30 to 40 years since onset sample among the males rather than any other significant factor. This was taken as further evidence that the sex of the respondents does not appear to contribute in any meaningful way to the results and thus justifies ignoring the sex of the respondents in the rest of the analysis of the information.

Of passing interest only is the magnitude of the experience of living with polio among the respondents, it amounts to a total of 63,574 years. Let nobody discount the contents because this study was not conducted under clinical conditions. The quotations speak for themselves.

Of the total forms returned, 1167 contained information that was used in the analysis that appears in the following pages. Memory must play a part in the accuracy of the first two responses in [Fig 6.](#), many were not able to remember if they were on a respirator or indeed whether they were hospitalised.

Again no purpose could be detected in favour of splitting the sexes for tabulating the statistics.

The intention was to isolate the reason for any type of treatment to those conditions directly attributable to the after effects of the polio, some of the responses make this area reliant to some degree on a subjective interpretation.

#### **Circumstances at onset and now.**

	<i>AT ONSET</i>	
<i>Hospitalised for over one month at onset</i>	917	79%
<i>On a respirator at onset</i>	225	19%
	<i>MOBILITY AIDS - NOW</i>	
<i>Uses wheelchair regularly</i>	652	56%
<i>Uses walking sticks</i>	491	42%
<i>Uses callipers on one or both legs</i>	425	36%
<i>Uses crutches</i>	190	16%
	<i>TREATMENT FOR EX POLIO CONDITION - NOW</i>	
<i>At orthopaedic hospital</i>	321	28%
<i>By GP</i>	274	23%
<i>At general hospital</i>	172	15%
<i>At special unit</i>	109	9%
<i>At pain clinic</i>	62	5%
<i>At rehabilitation unit</i>	44	4%

Fig 6. *Information about the onset and conditions now.*

## Changes since recovery

The number of cases which reported a marked change in condition was very high, [Fig 7](#) reflects the broader topics, followed by more specific conditions in [Fig 8](#).

<i>CHANGE SINCE RECOVERY</i>		
<i>Reported deterioration since recovery plateau</i>	895	77%
<i>Requires more help for day to day activities</i>	702	60%
<i>Had to leave/change work due to condition</i>	364	31%
<i>Had to leave/change work due to pain</i>	187	16%

Fig 7. *The principal changes since recovery.*

Responses in [Fig 7](#). were made against specific questions, whereas [Fig 8](#). and [2](#). represent conditions reported in the general supporting text and do not reflect the prompting of a leading question, it is reasonable to suppose therefore that they reflect a greater concern to the individual reporting them.

The only exception to this is the first response in [Fig 8](#). The section on sleep offered a response on fatigue while carrying out day to day activities, this was used together with the oft repeated endorsement of fatigue as being one of the most debilitating features of the whole condition. (See [Q8/9](#)) If this response is added to the next one in order of magnitude, the level of general overall weakness which can be difficult to differentiate from fatigue, then the importance of this area of effect on the individual and their lifestyle is obvious.

<i>SPECIFIED CHANGES SINCE RECOVERY</i>		
<i>Mentioned low stamina/high fatigue more than once</i>	774	66%
<i>General weakness reported as overwhelming effect</i>	671	57%
<i>General pain both muscular and joints reported</i>	313	27%
<i>Poor balance specifically mentioned</i>	174	15%
<i>Reported feeling the cold as a major feature</i>	78	7%

Fig 8. *Most frequent specific change mentioned*

Some of these reports have to be interpreted with a degree of caution. For instance, poor balance in all probability refers to a lack of the ability to make corrective movements with the legs in many cases, rather than any impairment to the balance mechanism. There is also a lack of definition between stamina/fatigue/weakness, and no doubt a degree of overlap has been included. That caveat must not be allowed to detract from the importance of this singularly authoritative message.

Pain is also to some extent derived from, or a product of fatigue, but many individuals reported pain unrelated to any particular activity or specific cause. The high frequency of arthritis and its associated pain must be a contributing factor in this response.

<i>SPECIFIC CONDITIONS REPORTED</i>		
<i>Breathing problems, not all requiring assistance</i>	189	16%
<i>Scoliosis</i>	195	17%

<i>Arm/shoulder problems due to using crutches</i>	185	16%
<i>Arthritis</i>	181	16%
<i>Had surgery to correct polio defect</i>	178	15%
<i>Reported frequent pins &amp; needles in hands</i>	59	5%
<i>Reported heart problem</i>	51	4%
<i>Has osteoporosis</i>	47	4%
<i>Has been diagnosed ME/Myasthenia Gravis</i>	8	1%

Fig 9. *Other specific conditions/problems mentioned voluntarily*

The reports of damage to upper arms and shoulders due to the prolonged use of crutches must be qualified by comparison with other factors. For instance only 64 or 34% of those who currently use crutches reported these problems as opposed to the 141 or 74% who reported the problem but now use a wheelchair. This probably indicates that acknowledging that the use of crutches can cause damage to upper limbs may lead to the adoption of a wheelchair as a more appropriate mobility aid. It is felt that this whole area is probably understated. There are many reports of respondents having to resort to the use of a wheelchair with loss of power in upper arms also mentioned, but the two situations are not linked. No assumptions were made in these cases, although one can remain suspicious.

Some of these responses need explanation which can be derived from the context in which they were made. For instance in most of the 8 cases when ME or Myasthenia Gravis was mentioned it was reported in the context of it having been given as a possible reason for certain symptoms rather than a positive diagnosis. In some cases it was reported as having been given to the patient in a dismissive manner as if to justify the view that the doctors time was being wasted!

The mention of heart problems can in all probability be dismissed as being in line with the rest of the population. In fact most of the reports were in connection with another condition such as persistent ulcers or general circulation problems, and as such have been ignored.

The incidence of breathing difficulty has a significant message. Of the 16% who mentioned this problem specifically, only 76, or one third had required a respirator at the onset, thus leaving 113 whose breathing has deteriorated to such an extent that they felt they had to report it. The significance is that these are the only involuntary muscles that are measurable in the survey, and therefore in some way the least subjective of all the evidence of deterioration in muscle power. See quotation [Q25](#).

### **Analysis of changes since recovery.**

In an attempt to predict the probability of deterioration taking place, [Fig 10](#) looks at the number of reports by date of birth and [Fig 11](#) is the same information but sorted by date of onset.

	<i>BIRTH</i>		<i>DETERIORATION</i>	
	<i>No</i>	<i>%</i>	<i>No</i>	<i>%</i>
<i>1909 to 1914</i>	84	7%	60	71%
<i>1915 to 1924</i>	265	22%	208	78%
<i>1925 to 1934</i>	308	25%	231	75%
<i>1935 to 1944</i>	216	18%	166	77%

1945 to 1954	288	24%	208	72%
1955 to 1985	51	4%	22	43%
<i>TOTAL</i>	1212		895	

Fig 10. *The proportion of those reporting deterioration by the date of birth.*

	<i>ONSET</i>		<i>DETERIORATION</i>	
	<i>No</i>	<i>%</i>	<i>No</i>	<i>%</i>
1909 to 1914	43	4%	27	63%
1915 to 1924	122	10%	92	75%
1925 to 1934	148	12%	112	76%
1935 to 1944	193	16%	139	72%
1945 to 1954	484	40%	368	76%
1955 to 1985	222	18%	157	71%
<i>TOTAL</i>	1212		895	

Fig 11. *The proportion of those reporting deterioration by the date of onset*

The figures in both charts are remarkably consistent, leading to the conclusion that the probability of deterioration occurring is neither age related or related to the elapsed time since onset, but to other factors. The only deviation from the consistent pattern in these sets of statistics is the lower percentage reporting deterioration among those born after 1955, but even this is in all probability cancelled out by the consistency of the data presented in [Fig.11](#).

178 reported that they had had surgery to correct defects related to polio, many were vague as to the nature of the corrective action so a detailed analysis was felt to be of little use. Of those who had surgery 149 or 83.7% also reported deterioration, see charts in [Fig 8 & 9](#), as opposed to 76.7%. The difference could be explained by the need for surgery indicating more serious effect in the first place.

To establish if there is any correlation between deterioration and the age at which the respondent contracted polio a detailed study was carried out, see [Fig 14](#).

### **Change in overall situation.**

A functional abilities chart was included in the survey form which although difficult for many to complete in detail due not the least to the passage of time, helped considerably in arriving at [Fig 12](#). This shows the change in muscle perceived by the respondent at three points in time. First as close to the recovery period as can be remembered, second at the very peak of recovery or muscle power, and third as perceived today.

All 1167 assessments were narrowed down to the relative position of 1 being the least affected through to 6 being the most severely affected. While the categorisation is somewhat subjective, in the main level 1 means no one limb completely affected, while 6 would represent total incapacity and full reliance on a respirator all night and a major part of the day as well. The shadings used are black "at recovery", grey at mid term or "best" and ladders representing the situation "now". To establish the degree of change for example from "best" to "now" look at the change from the number of yellow to red cases at each level (1 to 6). The bias toward blue, or "at recover" cases at the lower end of the 1 to 6 scale is obvious when

compared to the red "now" cases.

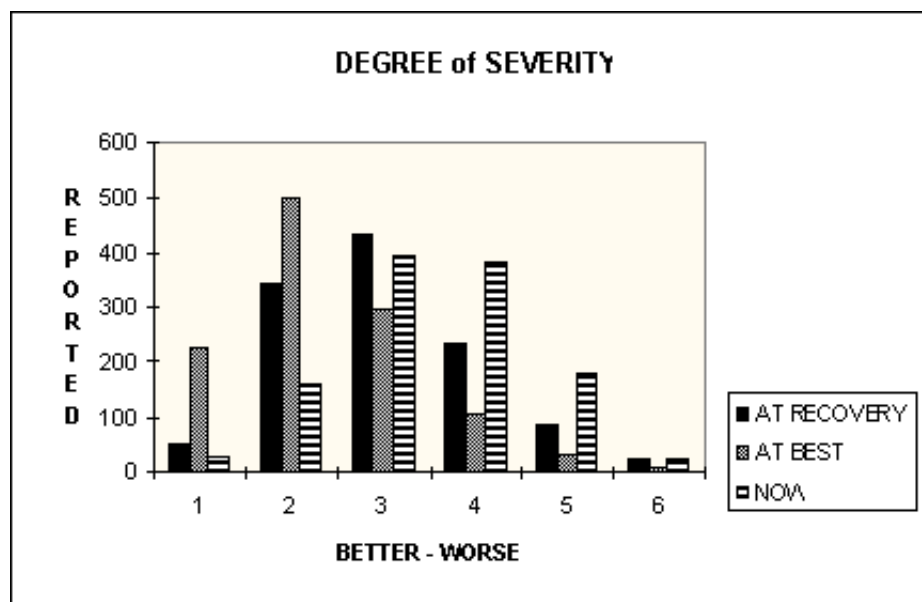


Fig 12. Chart plotting severity where 1 is best and 6 is most severe.

The actual numbers portrayed in this chart are shown in [Fig 13](#). It could be said that the table should only contain those who reported a deteriorating condition leaving out the 23% reporting a stable situation. It was felt that this way the pattern across all respondents demonstrates the gravity of the situation more graphically.

	No	%	No	%	No	%	No	%	No	%	No	%
SEVERITY	ONE		TWO		THREE		FOUR		FIVE		SIX	
AT RECOVERY	50	4%	343	29%	432	37%	236	20%	85	7%	21	2%
AT BEST	226	19%	501	43%	297	25%	107	9%	30	3%	6	1%
NOW	28	2%	158	14%	396	34%	382	33%	180	15%	23	2%

Fig 13. Number and % of cases shown in Fig 12

### Relationship of age at onset to probability of subsequent deterioration.

[Fig 14](#) was compiled in order to determine whether there is any correlation between the age of respondents at the onset of the acute phase and the probability of loss of muscle power, or any of the other unspecified symptoms of general deterioration. This is a detailed analysis of the cases of onset during the year 1950 using the three most common unspecific reports of signs of a condition existing which would point to the fact that deterioration was taking place, plus the unsolicited mention of unspecified pain.

		<i>A</i>		<i>B</i>		<i>C</i>		<i>D</i>	
<i>D o B</i>	<i>CASES</i>	<i>No</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>No</i>	<i>%</i>	<i>No</i>	<i>%</i>
UP TO 1925	11	8	73%	8	73%	9	82%	3	27%
1926 - 1935	13	11	85%	4	31%	9	69%	5	38%
1936 - 1945	24	20	83%	18	75%	16	67%	6	25%
1946 -1950	28	21	75%	18	64%	14	50%	7	25%
ALL 1950	76	60	79%	48	63%	48	63%	21	28%

ALL SURVEY	1167	895	77%	774	66%	671	57%	313	27%
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Fig 14. *Analysis of onset during 1950. Where: A - Deterioration. B - Reduced Stamina. C - General Weakness. D - General Pain.*

The remarkably consistent pattern of the results in [Fig 14](#) indicates that there is no relationship between age at onset and the likelihood of deterioration occurring in later life. Given the span of age at onset, with 11 over the age of 27 years, 5 between 20 and 24 years, and the rest falling between year of birth and 19 years, within the group studied, 1950 is considered to be a representative year as well as being the most prolific for polio among those who contributed to the survey.

If any further confirmation were needed, 1950 compares well with the statistics for the whole study, with a maximum deviation of 6% in the number of reports of General Weakness, which also happens to be the response with the greatest variation in the analysis of the 1950 figures.

## SUMMARY OF FINDINGS

The summary of findings are taken largely from the set of quotations detailed under that heading. However they are also substantiated within the statistical analysis. There are eleven important messages contained in the summary, as explained in the introduction to the quotations, these are considered to be the most important outcomes from the study.

1. Overwhelming fatigue is the most common and often the most debilitating condition. (See [page 12](#), [Fig 8](#) and [Quotations 8/9](#))
2. There is a statistically high probability that some deterioration, over and above normal ageing, will occur to those who had polio earlier in life. (See [page 11](#), [Fig 7](#) and [Q. 19](#))
3. There is evidence of deterioration in the breathing muscles controlled by involuntary action. (See [page 12](#), [Fig 9](#) and [text para. 2, page 13](#) and [Q. 25](#))
4. The demographic increase in age of the population will result in more polio survivors becoming increasingly disabled as they live longer, this will have an impact on the usage of and dependence on equipment provided by Health and Social Services. (See [Q. 2/5/10](#))
5. There is evidence of further lasting damage to already weakened muscles if they are subjected to enforced rest or immobilisation. (See [Q. 11/23](#))
6. There is evidence to suggest damage will result to upper arms and shoulders through prolonged use of crutches. (See [page 12](#), [Fig 9](#), and [Q. 8/14](#))
7. There are many cases of a dismissive attitude being adopted by medical professionals toward the symptoms experienced by "old polio's" (See [text foot of page 12](#) and [Q. 15](#))
8. There is a general lack of awareness within the medical profession of the implications of living with the after effects of polio. (See [Q. 1/15/21/24](#))
9. There is some support for the theory that hard exercising can do lasting damage to muscles already weakened by the effects of polio. (See [Q. 4](#))
10. There is evidence of excessive recovery times after relatively mild illnesses. (See [Q. 12/16](#))
11. Many respondents find if they pace themselves between tasks they can achieve more. (See [Q. 6/14](#))
12. The pattern of referrals must call for some comment. A high incidence of attendance's at Orthopaedic Hospitals, 321, is not supported by a corresponding number of operations, 178. There is also suspicion over the number of those attending rehabilitation centres and special units. Most probably brought about by terminology rather than a definable pattern. (See page 7)

## Conclusion



The summary of findings offers twelve significant points for possible further study. The mere fact that there are so many indicates that this is not a straight forward case of a consistent pattern of events that will occur at a predictable period after the initial onset.

There is no one conclusion to be drawn from the data revealed in this study, but if an overall prediction had to be made it would be that the message repeated throughout the survey is that deterioration, without doubt, can take place in later life. The pattern of the probability of the effect on individuals varies slightly, but there is a consistency which would attribute the chances of some deterioration becoming apparent at around 80%.

However the cause of the probable deterioration can still be called into question. That deterioration to muscular and skeletal strength does take place as a result of normal ageing cannot be questioned. To what extent that ageing process is accelerated within a body already damaged by polio earlier in life certainly has not been pinpointed in the findings.

A further complication encountered when analysing the data is the impact that other possible causes of deterioration will have on the same, already weakened body. Such symptoms as slight neuropathy brought about by diabetes could well be overlooked by the normal body, but have a quite devastating effect on an ex polio.

Is there any linkage between the incidence of arthritis and earlier polio. How does the 16% of cases reported compare with the national average at the same average age? The average age of those reporting the condition was 63.5 years, at an average of 55.3 years from onset. These figures are conveniently 3 years higher than those of all respondents.

Osteoporosis is commonly associated with loss of muscle power in the immediate area. At only 47, or 4% this seems remarkably low. Is this because of a general lack of awareness of the condition or does it imply that this is not a problem condition.

There is much food for thought for all who had polio some time ago.

*PETER FIELD*

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An Information Service for Polio Survivors and Medical Professionals

**All enquiries, book requests, medical article requests, membership fees, items for newsletters and donations to**

**The Secretary, Lincolnshire Post-Polio Network**

**PO Box 954, Lincoln, Lincolnshire, LN5 5ER United Kingdom**

**Telephone: [+44 \(0\)1522 888601](tel:+44(0)1522888601)**

**Facsimile: [+44 \(0\)870 1600840](tel:+44(0)8701600840)**

**Email: [info@lincolnshirepostpolio.org.uk](mailto:info@lincolnshirepostpolio.org.uk)**

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